HIT Privacy & Security Tiger Team
Draft Transcript
July 23, 2010

Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director
Good morning, everybody, and welcome to the Privacy & Security Tiger Team Call. This is a Federal Advisory Committee, so there will be opportunity at the end of the meeting for the public to make comment. Just a reminder for Workgroup members to identify yourselves.

Let me do a quick roll call. Deven McGraw?

Deven McGraw - Center for Democracy & Technology – Director
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Paul Egerman?

Paul Egerman – eScription – CEO
Yes.

Judy Sparrow – Office of the National Coordinator – Executive Director
Dixie Baker?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I'm here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Christine Bechtel?

Christine Bechtel - National Partnership for Women & Families – VP
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Rachel Block or Ellen Flink? Carol Diamond?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Carl Dvorak?

Carl Dvorak – Epic Systems – EVP
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Gayle Harrell? John Houston?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
David Lansky? David McCallie?

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Wes Rishel?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Micky Tripathi? Latanya Sweeney? Leslie Francis? Joy Pritts?

Joy Pritts – ONC – Chief Privacy Officer
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Adam Green?

Adam Green – Progressive Chain Campaign Committee – Cofounder
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Did I leave anybody off?

Judy Faulkner – Epic Systems – Founder
Yes. Judy Faulkner.

Judy Sparrow – Office of the National Coordinator – Executive Director
Judy. I'm sorry. All right. Good morning. I'll turn it over to Deven and Paul.

Paul Egerman – eScription – CEO
Good morning. I want to welcome you to our Tiger Team meeting. I want to welcome any members of the public, who might be listening. If you are members of the public listening, we very much appreciate your participation.

To briefly review: The Privacy & Security Tiger Team was set up with members from both, the Standards Committee and the Policy Committee for the purpose of making substantial progress on a number of privacy and security issues over the summer months. We have been meeting at an amazing pace; it seems like several times a week, but it's been approximately twice a week for three hours for each meeting. At the most recent Policy Committee meeting, which was held two days ago, on Wednesday, we presented basically the preliminary recommendations related to data collection, use, reuse and also preliminary recommendations on consent at a general level, not related to sensitive data, but at least at a general level.

I did want to report to the members of the Tiger Team who may not have been present for that Policy Committee meeting what happened, which was after we presented there was a spirited discussion about this whole consent issue, about the whole opt-in approach. I think that was a very useful discussion. There was an issue that I think Judy Faulkner raised related to directed exchange and sensitive data where there was a question about something that we had recommended and so we'll be talking about that, actually, in today's call. There were also some questions about how we had phrased some, how we had worded some of the issues on what we called the triggers for consent and I think Deven and I have a little bit of work to do to straighten out some wording to make sure that there's no ambiguity there. But over all, the Policy Committee endorsed what we did. They accepted all of our recommendations with the same understanding that everybody here on the Target Team has; that when we get all done we're going to re-present everything as a total package. When we do that there may be some changes or tinkering that we do on some of the past discussions so the Policy Committee will be able to see that total discussion.

So that is the progress and we're certainly very pleased. There was a lot of very positive comments from the Policy Committee; that they liked the way we had laid out all of the information on the data collection and use and reuse and the triggers and the meaningful choice and so that was positive. So, people here on the Tiger Team, I very much appreciate all of your efforts on this and you should also feel very good in terms of what the reaction is.

So here we have the agenda for today's meeting. Basically, the first thing that we will be doing will be to finish the other elements of the general consent discussion. If you remember, we actually had six questions on consent and we responded to the first three questions. We want to finish the other three questions and we'll walk you through those in a minute. Then we want to launch into this really tough and interesting issue related to sensitive data.

The way we're going to do that is a little after 11:00 we're going to ask John Houston and/or Leslie Francis, who are participants in the NCVHS process, to simply give us an update as to what's been going on there and what their recommendations are. To some extent, or actually, to a large extent NCVHS has done a lot of the heavy lifting for us on this effort so we have some good work there that we can build on. Then after hearing from them, we are going to launch ourselves into discussing the sensitive data questions.

Gayle Harrell – Florida – Former State Legislator
This is Gayle Harrell. I'm now on-line.

Paul Egerman – eScription – CEO
Good morning, Gayle. Thank you for joining us.

So that's basically the agenda. Unless people have questions about the agenda I think we should just dive into the consent questions.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
This is Leslie Francis. I also wanted to let you know I'm on-line.

Paul Egerman – eScription – CEO
Terrific. Welcome, Leslie. Thank you for your help. We're looking forward to your and John's presentation in a few minutes.

Rachel Block – New York eHealth Collaborative – Executive Director

This is Rachel Block. I'm on too.

Paul Egerman – eScription – CEO
Great. We're extremely pleased to have you, Rachel, especially since we have a lot of interesting consent and education and management issues we've got to talk about. You may have some very important, relevant experience.

So, Deven, having gone through the agenda, do you want to start walking us through, remind us of the fundamental principles and start with the first question?

Deven McGraw - Center for Democracy & Technology – Director
I sure will. Thank you. Thank you, Paul. This is, again, just a reminder of where we started in our general consent discussion and that is this fundamental principle that's on the slide now; that the relationship between the patient and his or her healthcare provider is the foundation for trust in health information exchange. There are two corollary principles that flow from that. The providers hold the trust and so, therefore, are ultimately responsible for maintaining the privacy and security of their patients' records. They may delegate certain decisions related to exchange to others as long as the delegation is done in a way that maintains that trust. Therefore, any decisions that we make about patient choice in exchange should flow from and be consistent with this fundamental principle.

Moving on from that, this is just a reminder of all of the questions that we put on the table for our general consent discussion. As you see, we took care of the first three. It's the final three that are in red on your screen are that we're going to tackle in the first, hopefully, hour of the call today. The first being, "Who should educate patients about their choice options? How and by whom should consent be obtained and managed?" And consent durability.

So we'll move right into the first question, which is patient education about choice and who should be responsible for fulfilling that function. Paul and I have taken the liberty of filling in some starter answers to get the conversation going, but of course, we are fully expecting that you all will chime in. Again, based on the fundamental principle that the provider holds the trust, it is at its core the patient's provider who holds the trust relationship who should be responsible for educating patients about their choice. Of course, it would be helpful for them to have resources to do this, because this is going to be new for a lot of patients and to help them understand and to create sort of model forms and notices and make sure that the choice is meaningful. There could be a role for the Office of the National Coordinator and the Regional Extension Centers or the RECs. There is probably also a role that HIOs could play. So, with that I want to open it up to discussion.

Christine Bechtel - National Partnership for Women & Families – VP
Deven, it's Christine Bechtel.

Deven McGraw - Center for Democracy & Technology – Director
Sure.

Christine Bechtel - National Partnership for Women & Families – VP
Thank you for taking a crack at the initial answers. I absolutely agree that providers have a significant role to play here, not only because of the trust relationship that exists between patient and provider, but also because I think providers can be very helpful in bringing clinical judgment into that conversation particularly and I think that relates especially to our conversation later today about sensitive health information where providers can play an important role in helping patients understand the clinical relevance of certain information that they may or may not want to protect in that regard.

But I'd also like to specifically enumerate the federal government at large, given Congress' establishment of this program and the federal government's running of it and the provisions I think I mentioned at a Policy Committee meeting in or around consumer education specifically with respect to electronic health information. So I think we should enumerate that the federal government, also in the context of the NHIN, has a really important leadership role to play.

Then the final thing I wanted to throw out there is that we think about the role of personal health record vendors as well. Their role may evolve and change over time based on technical capacities and the various exchange models that evolve. So I want to hold that out as something for folks to consider; that the private sector has a role as well.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I think this raises the question of what's an HIO. Is it an HIE or is a program, as designated under the specific grants that are going on or is it a more general case? If it's a more general case does the PHR vendor fall into the definition of an HIO?

Paul Egerman – eScription – CEO
It's a good question, Wes. I'm not sure I know the answer. In my opinion a PHR vendor is an HIO. I thought of an HIO as an HIE in the now. These are entities that are set up predominantly on a state basis, but not necessarily. There can be more than one in a state and there can be more than one state for an HIO, but these were the entities that were set up predominantly on a state basis.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
All right. I think it's important because the issue of who has contact with the patient is a consideration in answer the question who is responsible. One way to read the bullets is that the responsibility falls with the provider and other organizations that provide resources to the providers.

M
Right.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Frankly, I think these days there's nothing that a physician advises a patient about that they don't have about eight other resources for advice on anyway and I don't expect this to be any different. But if we're sort of establishing responsibility here, I think that has to be limited to those places that have contact with the patient.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I have two comments, one following on Wes' comment. As the reform bill created this new entity of accountable care organizations, which, to me, are closer to providing care than what we typically think of as an HIE because they have responsibility for the continuity of care for those patients, so I think in the scheme of things the ACOs would come closer to having some of the shared responsibility than perhaps the typical HIE.

The second question really is how are we defining educating? Does this include, for example, informing of policy, of various privacy policies of entities across the HIE, the ACO or whatever or other physicians or is it just educating them with respect to the implications of their choices? What all is included in that?

Paul Egerman – eScription – CEO
I assumed this was education about the consents decision, that choice—

Deven McGraw - Center for Democracy & Technology – Director
Yes and the elements that we had outlined as necessary in order for that choice to be meaningful that the Policy Committee endures.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
For each choice they can make at that point at that place in their care continuum, if you will.

Paul Egerman – eScription – CEO
Yes. So, for example, if it's an environment where there is going to be data stored for future use somebody has got to explain that to the patient.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I see. Okay.

Paul Egerman – eScription – CEO
Because that was one of the triggers.

W
Right.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
It's informing of the risks and their choices and the implications.

Christine Bechtel - National Partnership for Women & Families – VP
I think about the HIE or HIO, whatever we're calling them, the issue there is, number one, some of them, depending on the model that they use, will provide patients with direct access to their information, so I think the notion that entities that have contact with the patient still applies in that particular circumstance.

But I think to what Dixie was saying just now, it feels to me as though there's also a public responsibility for an entity that is going to hold and reuse data, whether or not they have direct contact with the patient. They're holding the patient's data and they're going to reuse it in accordance with the sorts of ways we've set out here in our meaningful choice. Then I think, at a minimum, they've got a responsibility to post some plain language information about who they are, what they do with that data and how the patient can go about making those choices. It may be so far as to say you need to contact your healthcare provider, but I think there is something that needs to be said by those entities.

M
I think we should write that in stone at the top. I mean I think that's a really basic principle.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes, I would agree. I think that from the perspective of the busy provider there's. Number one, they may not understand exactly how the data is being aggregated and what the constraints are for sharing with other people because they just don't have to learn that. They won't have time to actually spend time with the patient explaining it if they did understand it and what it will boil down to is the kind of pro forma, HIPAA acknowledgement that you sign every time you go see your provider and it's five pages of fine print and nobody is going to stop and explain that to you even if, in fact, they've met their obligation by having you sign this form that says you've read and understood it. So the place where any kind of meaningful engagement around the choice is going to occur is going to be the entity that's doing the

aggregation and controlling the access to the aggregated data. That's who ought to be on the hook for explaining how that access is controlled and monitored.

If there's an opt-out choice, which I think we've tried to push the notion that you should always have an opt-out choice it's that aggregating entity, the HIE, that will have the meaningful interaction with the consumer.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I think part of the problem though is that often the patient won't even know who or what the HIE is and that their only opportunity to ever have any contact will be through the provider, so it might be very transparent to the user. They may not recognize that the HIE even exists.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes. I mean the provider may say, "I participate in this HIE, but I suggest you talk to them to understand how this data is going to be managed and audited and accessed and how you can get accounting for disclosure, etc." I don't think the provider is going to be able to answer that question on his own. He may be the one to point you to them.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
I disagree with that, David. I think this is a conversation between the person who has a direct relationship with the patient. I don't think you can outsource the conversation about how to talk with the patient about their specific data and what will be shared and what the provider will be sharing. In every ... there will be some variation here and I do think that the provider ... has a responsibility to be able to have that conversation and also to make decisions about how they participate.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Carol, I agree in the ideal world, but in the practical world it will be a piece of paper that you sign.

Deven McGraw - Center for Democracy & Technology – Director
No, it can't be a piece of paper that you sign, David, because we have already said that where the factors are triggered the choice has to be meaningful and it has to have those elements in it and so I guess my additional response – I mean I get that providers are very busy, but if they're choosing an option that triggers that additional concern and is driving the traditional doctor-patient model into something that isn't necessarily what the patient would expect, then I feel justified in telling them this is how you've chosen to operate this. The obligation is still on you to educate your patients about this and get their choice.

Paul Egerman – eScription – CEO
I agree with what you just said, Deven, but I also want to pick up on comments—

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I just think that's very unrealistic and it will degrade into boiler plate acknowledgement and become meaningless.

Paul Egerman – eScription – CEO
David, let me make an observation. I wanted to pick up on a comment that Wes made that I thought was really helpful. A lot of patients these days get their information from multiple sources, so they won't necessarily only get their information from patients, from the provider. So the concept that I heard from Wes' comment was to do this right the patient's provider, who holds the trust relationship, is responsible for educating the patients.

But, for example, when you look at the HIOs, the HIOs should do two things. One is they should give help or information or assistance to the providers to tell them how to do that, but they should run their own Web site or something so patients can find out directly if they want to do so. The same should happen with ONC and the Regional Extension Centers, again, trying to hear what I think I heard Christine say. So on one hand the Regional Extension Centers, perhaps, but ONC should have information that helps the providers do their job, but they should also run some independent, ONC should run some independent Web site or information service that explains this thing.

Christine Bechtel - National Partnership for Women & Families – VP
Right. I think that would be consistent with what's called for ... it's Christine again. But I want to pick up on the it's just going to evolve into a nine-page form that people sign without reading. You know, I think the context here is important, which is that our context is that we're making recommendations to the federal government. The federal government has a number of policy levers that they can exercise with providers, with HIOs, with others. We've talked about them before, where they can really specify that this is meaningful education. They can provide best practices. They can provide plan language statements. They can better support a meaningful conversation between patients and providers.

So I don't want to assume that everybody is going to evolve into a meaningless form. I understand that's the case today, but I think we're talking about a different context where the federal government, at our recommendation, can leverage a lot of the various policy mechanisms they have to really make sure that conversation is meaningful.

(Overlapping voices.)

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I think it's very important that we educate the providers. Let's start where the education needs to begin. I think the entire thing through the RECs especially needs to happen so that the physicians, the providers understand what their responsibility is when they go into this. It's got to be a partnership all of the way down the road, starting from the RECs to the providers. The HIOs have to be very involved in providing additional information and resources to the provider. I think the ONC plays an extremely important role on the national level with the ... that they will have in order to have a national movement to understand what this means and people have education before they ever get into their provider. Lots of people use the Web now before they ever go to their provider. They know the questions they're going to ask up front. You can start that education on the national level so people are aware before they ever face the decision when they are going in to see their provider –

(Overlapping voices.)

Gayle Harrell – Florida – Former State Legislator
... program laid out in fourth grade language for everybody to be able to understand so that it's across the board. Everybody knows what is happening. If you don't have transparency in this you won't gain trust. It will not work without trust, the trust of the public.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes.

Deven McGraw - Center for Democracy & Technology – Director
Thank you, Gayle.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I still think we're dealing with a couple of issues: One, I don't think anyone would disagree with the notion that there needs to be a positive role in the government in creating resources of two forms; one that are directly accessible to any consumer on the Web and another set covering the same material that's particularly well suited for a provider to point a patient to. However, with the question of responsibility for education that, to me, implies accountability for education. There I think we're very concerned about nominality or how nominal is the approach and I think that if we look at informed consent for procedures as a model we find that participation of physicians has been effectively as nominal as they can get away with. The drivers towards meaningful consent have come as much out of liability concerns as anything else in the real world where they work and that we can hardly expect more, particularly if one of the options a physician has is to say, "Well, as a physician, I will opt-out of this health information exchange rather than commit my staff to another ten minutes to half an hour with each patient giving a meaningful consent—

Carl Dvorak – Epic Systems – EVP
I think I agree with David a bit more than maybe others do because I worry that if you think about the idealized patient in the primary care office with a doctor that's got time for him, you can maybe see a pathway for this. But I just see in our sites, in our county hospitals ... there are just patients streaming out of the ED that barely speak English ... qualified health centers. I just don't know. I guess I agree mostly with David on this one. I think it's going to be a lot less meaningful and a lot more perfunctory than we might imagine.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Carl, thank you for that. Carol, to your points, I absolutely think the physician is on the hook for the ultimate responsibility here, but in the practical world a patient, who really wants to understand what's happening with their data and find out how they can take greater control of it, the HIE or the entity, whatever it is, has to be on the hook also. So I guess I want to make sure that we aren't just transferring responsibility to the provider, who will be overwhelmed in terms of interacting with the concerned patient. So I'm not trying to get the provider off the hook. They absolutely own the trust and the vast majority of patients will do exactly what the provider recommends, without any question. That's fine, but if you have an engaged patient and they want to know more, the HIE can't be off the hook if this is meaningful. They have to be willing and somehow able to engage with the consumer.

Paul Egerman – eScription – CEO
That's particularly important. This is Paul. I agree with you, David. It's particularly important because each one of these HIEs or HIOs is going to be different in each state.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes.

Paul Egerman – eScription – CEO
So the information is a little bit different in terms of what is being presented. The HIEs and HIOs do play a major role.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
I am not adverse to transparency to the patient of whatever the entity is that is participating in this. What I am suggesting, however, is that the conversation about which of the patient's information, how the patient's information will be shared and with whom has to start with the provider and the person who has the relationship with the patients. You're not going to send the patient to the HIE to discuss which of their sensitive health information or how their health information or which particular element of their medical

record will be shared without the provider's involvement. I think it's critical that the relationship of trust that the patient has with the provider be maintained.

You know, I think there are historically lots of failures in the implementation of IT when the attempt is to try to use IT to kind of override or change the way the relationship and the trust exist in the analog world. I guess I'm just saying that the patient's expectation and the trust relationship have to be preserved in however we make this recommendation.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
If I might chime in, I agree with Carol. I think though probably the one area that concerns me the most about having the communication occur with the provider; again, I think it's the thing to do; is to make sure that there is a consistent, comprehensive and clear set of, I don't want to say talking points, but the message is consistent between providers and I think that's probably going to be one of the most problematic things of assuring is just that. I mean different providers emphasize different things or don't emphasize anything, depending on where the patient goes, they could get a totally different message. I wonder how we're going to ensure the consistency and comprehensiveness of the message.

W
I just want to frame this a certain way and maybe this will be helpful to the discussion. Some of the conversation about the consent potentially being perfunctory, it's really important for us to sort of go back to where we started, which is this is not consent in lieu of all of the elements of data protection and privacy and security that we talked about, all of the other sort of fair information practices. It is along side and with those protections. I think it would be very valuable to sort of think about this model "consent" in the context of a complete framework, not on its own. I would also recommend it would be very valuable for ONC or whatever the appropriate agency is to provide model language that can be used with consumers that makes all of the sort of elements of this very, very clear and said in plain language. I think without that you do end up with the seven-point font, long documents that are really hard to read. I think everything we do on this consent issue has to be done in the context of the complete framework, not just consent on its own.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I want to do a thought experiment and, Carol, I'd be curious to know what your thought about this is. Paul, I'm going to break one of your rules and bring up a subject that we haven't talked about yet, but I'm just using it for the thought experiment here. Let's assume we get to the point at some point in the future when the consumer has some say-so over granular consent—

W
Right.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
You know, they can decide what to segregate or who can see their record. Would the service where they understand how to take control over that granular consent, would that be required to be offered by the provider through his system or by the HIE or we don't care?

My concern is that in order to take that control you're going to have to have some pretty significant hand holding and support and I have a hard time imagining that that's going to come from the provider.

Paul Egerman – eScription – CEO
Yes, but that is a separate issue that we haven't addressed.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
No, I understand; but we will address it.

Paul Egerman – eScription – CEO
... as I said before, to go back and revisit issues based on an understanding that we get when we address something in the future.

Deven McGraw - Center for Democracy & Technology – Director
Yes.

Paul Egerman – eScription – CEO
So I think we need to stick with this issue.

M
I'd like to suggest that we have almost unanimous consent on principles.

Deven McGraw - Center for Democracy & Technology – Director
I think we do too.

(Overlapping voices.)

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
But we have significant skepticism, a significant range of belief about the degree to which the principles will be upheld. I think one of the things we all agree on is that any chance of meaningful consent coming through the provider depends on getting language out there that was not written by lawyers in order to protect their clients.

Deven McGraw - Center for Democracy & Technology – Director
Right.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
And I also think that, frankly, I've been conditioned by reading the NCVHS letter in my discussion, so I might go more to the skeptical side if I were to believe we were really going to allow people much more fine grain control.

Paul Egerman – eScription – CEO
That was a great summary, Wes. It seems to be the basic principles we've got for this one is we wanted to maintain the patient-provider relationship and that means, to answer the question, the provider is responsible for educating the patient. But then we also want to help the provider be successful and so that means that ONC and the federal government and the HIO and the RECs have to provide help, resources or help to make this happen.

Then we're also saying that in addition to providing those resources to the provider to help the provider, ONC and the HIOs should be operating their own independent educational service, probably through a Web site, but some educational services to consumers, if they can find a way to those entities, can independently be educated. Those are the basic principles we have.

Deven McGraw - Center for Democracy & Technology – Director
Yes. I've actually been taking notes on this conversation. Are folks not able to see my—

Paul Egerman – eScription – CEO
It looks good to me.

Deven McGraw - Center for Democracy & Technology – Director
Okay. I just wanted to make sure that I wasn't just privately taking notes over here.

Judy Faulkner – Epic Systems – Founder
I think what you said, Wes, was good. I especially was interested in your comment that lawyers shouldn't write it. I think that you're right in one way; in that I know that with the lawyers I work with, even when they're trying to write something that's just every day language it ends up being legal ease because that is their every day language and they don't see it. That's pretty typical. I mean I'm sure that there are exceptions, but in general it's very hard for them to realize that what they're writing is hard for others to read. Yet, I think that many of the healthcare organizations will still turn to lawyers to write it or to edit it because they'll be afraid that if they don't it simply will violate something and they'll be liable.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
That's why I think the model language is important. I think obviously you have to rely on your lawyer unless you want to be voted out by the board. What we want to do is give the lawyers some cover for what is accepted practice in writing these statements by having them prepared in a model that includes both, legal review and participation from those who really know how to write at a fourth-grade level. I mean insurance companies do this now. There's got to be a way to do it. I mean it's just not the process you get if you simply go to the lawyer and say, "I need something that complies with this regulation." I agree; it will have been reviewed by lawyers before it's ever published.

Judy Faulkner – Epic Systems – Founder
Yes, but I just want to point out this nuance; that the advantage of having ONC do some model language is that the "lawyers who might write this are writing it from the perspective of really protecting the consumer, the patient." Very often the client and the lawyers that we're talking about is the provider or the data holder and I think balancing both of those perspectives in this model language is really important, not just to write this from the standpoint of protecting the provider, but to write it in a way that offers meaningful protection to the consumer.

Paul Egerman – eScription – CEO
Those are good points. I think that's what Deven wrote on the screen. I apologize. I probably should point that out; we do have a lawyer writing the notes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I want to raise one more point of skepticism. Maybe my role this morning is the designated skeptic, but I like the language about the notion of model language and clear understanding. This kind of assumes that there's just one way that this status sharing occurs. We need to be cognizant that there will be many of these things occurring and some of them will have varying degrees of optionality for the provider and optionality for the consumer, so there's going to be more than one set of language and more than one model out there. As Dixie mentioned earlier, the accountable care organization, data sharing will be a non-optional one, but it will be, in fact, widespread data sharing—

M
I think as we discussed before, the accountable care organization ... information exchange ... might not be information exchange—

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But that's what's being built today across boundaries and a lot of data sharing is going to happen under those rubrics. In fact, I predict that will dominate the data sharing in our communities, because of the business case behind them and they will be the ones that survive.

Deven McGraw - Center for Democracy & Technology – Director
Do you want to move on to the next one? I think we've got this one—

(Overlapping voices.)

Paul Egerman – eScription – CEO
It looks good.

Joy Pritts – ONC – Chief Privacy Officer
This is Joy.

Deven McGraw - Center for Democracy & Technology – Director
Hello, Joy.

Joy Pritts – ONC – Chief Privacy Officer
Is Micky on the phone today by any chance?

Deven McGraw - Center for Democracy & Technology – Director
No.

Paul Egerman – eScription – CEO
No. He couldn't make it.

Joy Pritts – ONC – Chief Privacy Officer
Because I think he would have some very valuable insight on ... issue, because they actually did a lot of communication to the community and consumers in Massachusetts when they were developing their pilot project among the three communities there.

Deven McGraw - Center for Democracy & Technology – Director
No. Undoubtedly, Joy, and we will ... to him— Is this Rachel that's chiming in? I mean, look, the ability of an HIO to do some community outreach is important and I think we emphasized that, but it's not a replacement for conversations with the physician. It's additive. It bolsters. It supports.

Paul Egerman – eScription – CEO
Also, Joy, I did reach out to Micky. Unfortunately, he couldn't make it to this call, but I tried to get him to give us his thoughts on these issues and I'm still trying to do that.

M
Deven?

Deven McGraw - Center for Democracy & Technology – Director
Yes?

M
I'm not sure that it belongs on this slide if there is room, but somewhere in recording this I think we need to observe that the consequences of making this too complicated would be drop out at the provider level.

Deven McGraw - Center for Democracy & Technology – Director
Right. Okay. I'll make note of that because ultimately, again, when we want to wrap up these recommendations in a complete package I think we want to surface all of the permutations in a much more clear way, so we'll make note of it and make sure that it gets included.

Paul Egerman – eScription – CEO
I think we've got—

Gayle Harrell – Florida – Former State Legislator
I'd like to also emphasize the transparency needs to be there. I noticed that you've put the HIO must be transparent in its functionality and operations. I think that is extremely important; that they play a real role in that transparency to the provider and also to the patient and that this very obvious, that there needs to be some partnership there with that.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I like that. I agree.

Paul Egerman – eScription – CEO
Great. Are we ready to move on to the next one?

Deven McGraw - Center for Democracy & Technology – Director
Yes. I think I can just go to the next slide.

Paul Egerman – eScription – CEO
Yes, because actually, once it's in this mode I can't control the slides. You've got to do it.

Deven McGraw - Center for Democracy & Technology – Director
Yes. No. No. No. They're on my desktop. I'll get there. Hold on.

Paul Egerman – eScription – CEO
Okay. We wait with great anticipation for the next slide here.

Deven McGraw - Center for Democracy & Technology – Director
Here you go.

Paul Egerman – eScription – CEO
Okay. So this is the next question: Who obtains and manages the consent? And the way we phrased this, the suggestions that Deven and I wrote here to start the discussion was provider obtains and is responsible for management, but depending on the model, the provider can delegate management to the HIO, perhaps in some models the HIO can provide some function or something that helps the provider manage the consent.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I mean, again, one of the models we're talking about, again, I thought was opt-out. The idea of a consent is incompatible with the idea of opting out.

Deven McGraw - Center for Democracy & Technology – Director
What?

Paul Egerman – eScription – CEO
First of all, when I mention model I'm talking about model of the HIO, in other words, whether it's centralized data or a federated model and whether it's opt-in our opt-out. Somebody has got to obtain the information from the patient, which I think is the provider, and somebody has go to manage it. Manage it means you've got to some how keep track of records or something of what happened.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I mean my point is let's assume there's an opt-out model. There really isn't a consent by the patient. The patient would say I'm opting out of being part of this HIO; otherwise, by default, if the patient doesn't opt-out all of that simply occurs and so there really isn't a consent, per se.

Paul Egerman – eScription – CEO
Well, even opt-out is still a form of consent and if somebody opts out you have to keep track of that.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Okay. I just want to clarify that there isn't a consent in the classic sense of that opt-in we're talking about. I just wanted to make is clear—

Paul Egerman – eScription – CEO
Yes. Who obtains and manages is really the consent decision or the choice decision.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Thank you. I think that's clearer.

Paul Egerman – eScription – CEO
Okay. I see what you're saying. That's the way I was looking at the issue. In other words, opt-out is a negative consent. I view that still as a consent ... a negative consent—

(Overlapping voices.)

Paul Egerman – eScription – CEO
Somebody has got to do something and manage that.

M
When people talk about consent the first thing people think about is a form that you sign and there's all of this. That really isn't the case. It's how do we manage that notion that the patient has either decided to or not to be part of the HIE or the HIO.

M
Consent is a noun or consent is a verb.

Paul Egerman – eScription – CEO
Right.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I have some questions here. The third issue you might ask is who operationalizes the consent. Are we assuming that's always the HIO or sometimes the HIO? That is if the data is no longer reposed solely with the provider then the provider can't be the implementer of the consent.

Paul Egerman – eScription – CEO

We already answered that question, David.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
It's Wes.

Paul Egerman – eScription – CEO
I'm sorry, Wes. The concept is that that part of managing the consent that happens on the provider's side. If a patient says, whether it's opt-in or opt-out, "I don't want to participate in that exchange," that means their data is not sent to the exchange.

Now, in the next discussion we're going to deal with what happens if the patient changes their mind after it's sent, but the first one is if they're not going to participate in the exchange—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
The term manages here doesn't mean what happens if the patient changes their mind?

M
Pardon me?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
You've got the word manages in this slide and I apparently misunderstood what you meant entirely by the term manages.

M
Well, maybe ... manages the initial patient's choice. There is an initial choice and there's the durability of the choice, which is the next question. It's what happens when the patient—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Okay. Well, there are two questions here. One is what is the meaning of the consent that a patient gives an individual provider? Does it mean solely for that provider relationship? In effect, does the patient have to have that conversation with every provider?

M
I think that's very key. That's, I think, what led to some of the confusion in the previous discussion is I was thinking to if one way and maybe, Paul, you were thinking of it the other. The provider is only being responsible for his own data stream, if you would, to the sharing agency and I'm thinking of the broader context of it all aggregated together.

Paul Egerman – eScription – CEO
Well, yes. But I mean first of all it depends on the state. In some situations it may never be aggregated together because it's hard to know how the HIE or HIO is managed, but the basic premise we had when we did the consent discussion was that we were going to start with the patient-provider relationship. That means if the patient decides not to participate through whatever choice model that is then none of the data is sent.

M
But I'm asking the question when the patient tells Dr. Welby that I don't want to participate or I don't want my domestic violence information shared then who is bound to implement that? Is it only Dr. Welby?

Paul Egerman – eScription – CEO

Only Dr. Welby. The patient has to say that to each provider, and provider being provider entity. In other words, if they belong to like a multi-specialty group they probably only have to say it once, but if they have a separate, say, dermatologist that they go to that's not associated with their group they would have to make that choice with that person also.

Judy Faulkner – Epic Systems – Founder
When you look at this information, if you're getting it in advance, like is your hypothesis as you're discussing this, then I think the model of that provider works okay. But if the patient hasn't done anything in advance and shows up at another provider organization then that second provider organization has to have the responsibility to obtain the consent in place of the first provider organization, because the patient is physically at the second. So it begins to get fairly confusing. If you have an HIO that is an HIO that's a community HIO it may be that it's more beneficial for everyone if the HIO is handling it. I'm wondering with all of these different ramifications if we go back to the basic premise and let them choose which way it works.

Paul Egerman – eScription – CEO
I don't know what you mean by community HIO.

Judy Faulkner – Epic Systems – Founder
Oh, okay. A RHIO, for example, that is keeping a lot of the information for New York City. So wherever I go within New York City I know that my data is going to be in there and if I see a lot of different doctors, it may be simpler for me to do it that way. I'm just saying that as we try to think of all of the different permutations of this to make sure that our rules don't really harm the way people work. I'm just hypothesizing that and I'm wondering if, in fact, we should put out some suggestions, but let them decide based on what's best for their community.

Paul Egerman – eScription – CEO
Well, except doesn't that change this whole concept that the patient-provider relationship is primary?

Judy Faulkner – Epic Systems – Founder
Yes, but that's why—

Paul Egerman – eScription – CEO
Let's say New York City it's decided that everybody is going to go into the same RHIO and that means then I go to my physician and the physician doesn't have to tell me anything, because he assumes I know it already?

Rachel Block – New York eHealth Collaborative – Executive Director
This is Rachel—

Deven McGraw - Center for Democracy & Technology – Director
We're talking about New York, Rachel. We're just cuing you right up.

Rachel Block – New York eHealth Collaborative – Executive Director
... use a real life example and I think it actually speaks back to the earlier discussion, but what we try to do is identify appropriate roles and responsibilities throughout the whole continuum, so what's the patient's role and responsibility? What's the provider's role and responsibility? What's the RHIO's role and responsibility? Just having a RHIO doesn't mean that it in any way alters; I shouldn't say alters. I think this a little bit of what Carol Diamond was trying to say earlier. It doesn't mean that the provider doesn't continue to have a responsibility.

The RHIO may assume certain roles relative to supporting the provider and ... that responsibility. We don't currently have a scenario where anybody is required to join anything. These are bottom-up, multi-stakeholder government entities and participation is voluntary. We'd like to think there are benefits to participating, but there currently is not any sense of mandatory participation.

So I don't know if that helps a little bit, but again, I just think it helps to be clearer about if what we're particularly trying to focus in on here is are there sort of unique responsibilities that we believe we want to try to articulate that really belong to the provider in the context of that provider's relationship with the patient. Maybe that's one level is all of the other sort of operational and technical assistance activities that really help to make that provider and patient relationship as strong and well informed as possible.

Paul Egerman – eScription – CEO
Actually, extremely helpful comments, Rachel. I appreciate that. I especially appreciate your comment that participation is not mandatory. That's a very important comment. Since we—

Rachel Block – New York eHealth Collaborative – Executive Director
We were talking about changing that and there are some states that have gone that direction, you know, Vermont in particular, but that's a little bit of a discussion down the road.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I'd like to suggest that our principles should apply irrespective of the model they have to take into account the variability and model—

Paul Egerman – eScription – CEO
Wes, let's just go back to what Rachel said, which is participation is not mandatory. Now, there could be some states that pass a state law that changes that. That's why that's up to them, but absent any state legislation, participation is not mandatory, so the impact of a choice decision to not participate means you don't participate, which means your data is not sent to the HIO. Right? We're not talking about directed exchange. We're only talking about a model where there's some entity, some third party entity that's going to be involved with the data.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I also question the assumption of whether there's a single HIO.

Deven McGraw - Center for Democracy & Technology – Director
Yes. There isn't. Can we get back? This seems to me to be a relatively easy question to answer if we can have some discipline in not trying to go too far down in the weeds of different models, because we acknowledge that there are likely to be many of them. The fundamental principle being, and we've already stated that the patient-provider relationship is where sort of choice decisions emanate. To me this slide is more about who operationalizes it and it's going to be different depending on the model and so the basic principle of the default is a provider, but that could be delegated to manage depending on whether that makes sense based on the model. So it's about who sort of pulls the lever back and forth to honor and support the preferences that were made in accordance with the principles that we've already agreed to.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I guess if we are limiting this to initial choice and preference for information from a given provider—

Deven McGraw - Center for Democracy & Technology – Director

Right.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Then I think your bullets are fine. The difficulty I have is two-fold: One, as Gayle frequently points out, this is partly about establishing patient trust for the stewardship of the information. That's very dependent on the model.

When a patient over a period of time has relationships with providers that change so that their primary care physician changes, then have they lost all control over the information that was provided by their first primary care provider? So as long as you very tightly constrain this then I think the answers are easy. If not, we need to discuss it more.

Paul Egerman – eScription – CEO
Yes and each provider is just going to contribute a little bit to a big picture. I don't know how you can expect each individual provider to have any sense of responsibility for the big picture, for their piece of contribution, yes; for the spigot to turn on their flow, yes. But that's not what's going to be of concern to people.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I'm imagining a scenario when somebody realizes suddenly that information that's in a sensitive area will be shared if they don't update their consents and now they have to go back to eight or ten different physicians, who don't even have a doctor-patient relationship with them any more, and say, "I want to change my consent."

Paul Egerman – eScription – CEO
To try to simplify—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
This is Dixie Baker—

Paul Egerman – eScription – CEO
Wait. Wait. Wait. To try to keep this ... simple what we tried to do is to say this is for the initial choice. So if the initial choice is this, this one should be simple. This is like day one. We're getting started, whether it's opt-in or opt-out, somehow there is a decision being made whether or not to participate. To me it's simple. The decision has to be taken by the provider and the provider is responsible to manage that or keep track of it. So maybe the word managing is causing some concern, but at least ... is responsible for record keeping of the decision, except to the extent that the HIO provides some resources to assist the provider, so that becomes like a delegation kind of thing.

Adam Green – Progressive Chain Campaign Committee – Cofounder
Paul, can I get—

Paul Egerman – eScription – CEO
Yes. I'm sorry. Who is that, Adam?

Adam Green – Progressive Chain Campaign Committee – Cofounder
Yes. Although I know Dixie was speaking up before, so I can go after her.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes. The point I wanted to make is that we just had this hearing on consumer choice and we had a whole panel that at least two of the four talked about the new model of having privacy management as a service. You'll recall that Robert Shelton from Private Access was on that panel and he talked about Private Access is offering permission management as a service. That model and his company seems to be getting a lot of attention these days, the point being I don't think that we should come up with anything here that makes such a model impossible, because I think that it's an innovative approach and in fact, it would make privacy management or consent management much easier if it were centrally managed as a service, so I don't think we should say anything here that would preclude that model's being used.

M
Yes.

Paul Egerman – eScription – CEO
Is there anything here that does preclude that, Dixie?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I think the first bullet does, yes.

M
I don't think—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I think it does because in Private Access, for example, Private Access receives, obtains and is responsible for keeping track of permissions.

Deven McGraw - Center for Democracy & Technology – Director
Yes, but that's under a delegation.

Paul Egerman – eScription – CEO
It's a delegation. Yes. I mean if you take—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
... delegation. The provider purchases, subscribes to Private Access as a—

M
That's a delegation.

Paul Egerman – eScription – CEO
That's a delegation. Just like the provider could be responsible for having a ... that doesn't really—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I think that first bullet, obtains and is responsible for obtaining, precludes that model.

Paul Egerman – eScription – CEO
I don't think so.

M
Oh, no. I think the problem is in the second bullet, where we say ongoing management. I think we want to allow them to, if they want, to delegate obtaining the permission too.

W
Are these two bullets one versus the other or are—

M
No.

Paul Egerman – eScription – CEO
No. No. They're cumulative.

W
They're cumulative. Okay.

Paul Egerman – eScription – CEO
Yes. So—

W
Yes. Then I like them.

Paul Egerman – eScription – CEO
So we fixed your issue, so responding to both David and Dixie, it says a provider can delegate these functions to intermediaries/HIO—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Now, obtaining in the first one; if I'm a provider and all I do, I go into a provider and I say, "Private Access has all of my permissions. You can go out there and get them and give them permission to go and get my permissions," that would be equivalent to obtaining in the first bullet?

Paul Egerman – eScription – CEO
Yes.

M
Yes. And further more, the provider would be taking a legal responsibility to trust Private Access. I mean they haven't delegated their responsibility. They've only delegated the mechanism by how it was obtained.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I like the direction we're headed, but I'm confused. It seems very clear that the provider has responsibility for, let's call it, the initial release of the information and the ongoing release of information. So if the consumer says, "I don't want you to share this with the local sharing entity," the provider has responsibility to respect the consumer's wish. I think we're saying that's clear. What I'm less clear about is subsequent access to that information after it's been released from that provider's record. Are we addressing that or is that a future—

Paul Egerman – eScription – CEO
No. That's the next question.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Okay. So we're just talking about the flow out of the provider's record into whatever service is record locating or aggregating or whatever?

M
Right.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Okay.

Paul Egerman – eScription – CEO
I think in the midst of all of this Adam was trying to say something. Did you—?

Adam Green – Progressive Chain Campaign Committee – Cofounder
What I was just going to add is I see there being somewhat two levels of consent in that a person may want just that particular provider not to put their information into the HIO or it may be that they don't want any participation in the HIO. I'm wondering if that really changes the dynamics of this significantly, because if you don't want any participation in the HIO it seems that we don't necessarily want you having to go and opt-out at each provider.

M
We've been told not to think about that yet.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Well, but it is a very important reason for not uncoupling the obtainment of consent from the provider. I really think that there is a danger there in having the entity that is potentially going to manage the data collection or the information exchange being in the position of talking with the patient about whether or not and how and which data and which information goes into it. The entity that's exchanging the information has to only get the information that a particular provider has on a particular patient after that conversation and not try to do all of this at the HIO level, hoping the patient knows all of the different providers that hold their data, because we usually don't.

Paul Egerman – eScription – CEO
That's right ... what you said, Carol, is right. It seems to be, from the patient's prospective, the safest thing is to simply tell your providers not to send the data if you don't want your data sent.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
That's right. I don't want—

Paul Egerman – eScription – CEO
If you have to rely on this service that really wants to get to the data to not receive it that's a tough one. I mean it would be nice if it worked and it might work, but purely patient autonomy standpoint, that's what you would do.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Right, which is why I don't think we should delegate obtaining the consent aspect. Also again, because this is nested in the other provisions of privacy protection that we've discussed around fair information practices, it is a package of a conversation. It's not just, "Hey, you consent."

Paul Egerman – eScription – CEO
It's a good point. The delegation though, in my mind, was not delegating the responsibility; it's delegating the administrative function.

W
Yes.

Paul Egerman – eScription – CEO
In other words, we need to be clear that you can delegate the administrative function either to the service, like what Dixie described; perhaps the HIO provides that service in some way to help the provider and that would be fine too.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Well, I do think Carol points out an important issue here, which is that the model – when I first saw the second bullet my model was well, the doctor might use software provided by the HIO to record this. But then, as Dixie added, the notion of some firm that's out having direct contact with patients and educating them on their consent and then recording their consent and said we shouldn't rule out that model, we did change the tenor of the discussion more substantially than I first realized.

M
I think we're blurring initial release and subsequent—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
No. I'm doing my best to confine my discussion here to initial—

M
Initial release.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Initial release. In other words, Dixie raised the model of a company that goes out as a service; contacts consumers; says, "Here's what you need to know in order to provide insurance. If, by the way, all of your providers use our service and you record it here and then when you go to the doctor you just give them this card." The doctor, therefore, will trust us that you have been educated properly on the services to meet his legal requirement and we just won't go through the discussion with you again." That's a case that I think really does – that's more delegation than I had realized initially.

W
But I think we're compounding models here. We should stay focused on the model where the provider is primarily making a determination about participating in health information sharing on some level. There is the model where it's consumer initiated and I think that's a separate discussion.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
But I don't understand Dixie to be trying to compound the model. I understand her as saying that there are people, who offer these services to physicians and who, therefore, could qualify as delegated provided that the physician had a relationship with these third party services.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
But in truth, how it actually would be carried out I think just from legal considerations, as somebody brought up before, I think what would happen is that it would be private branded or something and still would be the—

W
What?

Paul Egerman – eScription – CEO
... Dixie, you're breaking up.

Deven McGraw - Center for Democracy & Technology – Director
Yes, Dixie.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Oh. Can you hear me now?

Deven McGraw - Center for Democracy & Technology – Director
Yes.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Okay. I'm sorry. I think from a legal perspective I think that what would happen is that service would be licensed and privately branded by the individual physician and it wouldn't be this; sort of like the relationship with the PHR—

Paul Egerman – eScription – CEO
I don't have any problem with the mechanism being delegated as long as the accountability and responsibility stays with the physicians.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Right.

Paul Egerman – eScription – CEO
That's what we've got here. The provider has the responsibility. The provider can delegate the administrative functions.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes. I think that's right.

Paul Egerman – eScription – CEO
The whole reason for that second bullet is either for the service Dixie described, maybe the HIO provides something that makes it easy for the provider to record it. That would be a nice thing to do. It would be in everybody's best interest if that occurred to minimize the administrative hassle.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Or ACO as well.

Paul Egerman – eScription – CEO
Whatever the organization is.

M
But that's, I think—

Paul Egerman – eScription – CEO
Let's not make this harder than we need to. I think we've got agreement on this. Providers are responsible. It's okay for administrative support to be given to the provider. Do we have agreement on that?

M
Say that again.

Paul Egerman – eScription – CEO
The provider is responsible for obtaining the consent and keeping track of it. The provider can get administrative support from other sources; the HIO or somebody else can give them some tool or something to record it. That's fine too.

M
But the—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
We're talking only about access to clinical data only, right?

M
We're not talking about access. We're talking about contributions.

M
We're talking about the triggers.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I meant the permissions, consents relating to. This—

Paul Egerman – eScription – CEO
Dixie. Dixie. Dixie. Dixie, we are talking about— This is question number five of six related to consent and so this is consent that was caused by those triggers that we just provided.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Okay. Those triggers. Okay.

Paul Egerman – eScription – CEO
So remember, the triggers. It's fair information practices. It is not directed exchange. It is the triggers.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Right.

M
But, Paul, the focus here is on the contribution of the information; not on what happens to it after that.

Paul Egerman – eScription – CEO
The contribution? This is only talking about keeping track of whether or not the patient gave consent. This is not about keeping track of anything else. This is just—

M
But gave consent to have the data flow into the HIO?

Paul Egerman – eScription – CEO
That's correct.

M

Okay. What happens to it in managed after that is another discussion?

Paul Egerman – eScription – CEO
The data itself?

M
Yes.

Paul Egerman – eScription – CEO
Yes. That's not what we're talking about. We're only talking about keeping track of the decision, however it was done. Yes. No.

M
And to contribute. I mean the key word there, to me, is contribute.

Judy Faulkner – Epic Systems – Founder
Paul, the concerns I've seen some of the healthcare organizations have is how do you keep track. So does it have to be on paper or can it be electronic has been one question I've seen.

Another question has been if the patient hasn't expressed any consent that is required, if it would happen to be required, and shows up at organization B, does organization B have to send a copy of it physically to organization A if organization B gets the patient's signature.

Paul Egerman – eScription – CEO
Well, again, you're talking about a directed exchange situation—

Judy Faulkner – Epic Systems – Founder
No. No. I'm not. It could be anything. It's irrelevant whether it came through an HIO or whether it came through directed exchange.

Deven McGraw - Center for Democracy & Technology – Director
I don't know why we would want to—

Paul Egerman – eScription – CEO
Here's my answer, Judy. Whether or not it's on paper is not this question.

Judy Faulkner – Epic Systems – Founder
Good, because then I think—

Paul Egerman – eScription – CEO
That is not this question. This question is what it says. Who obtains the initial choice?

Judy Faulkner – Epic Systems – Founder
But if you—

Paul Egerman – eScription – CEO
Somebody else is going to tell us whether or not it's paper or electronic.

Judy Faulkner – Epic Systems – Founder

Well, I do think, because I've seen it be such a concern and I don't think it has anything to do with which method it is, I think because it's a concern I think it would be worthwhile for us to say it could be either.

Paul Egerman – eScription – CEO
That could be, but that's not what we're being asked to answer. What I—

M
I hear Judy raising two points.

Paul Egerman – eScription – CEO
Whatever it is, all we're saying is that the provider is responsible and so whatever the administrative function is, the provider can use some outside service to help them with it.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
So the problem we're having is usually people not being clear on the implications of what they're agreeing to and therefore, wanting to qualify them. You've done a great job of corralling those implications, thus extending the other things we have to talk about, but maybe making some progress.

Judy has raised a point that I haven't heard and considered at all, which is the issue of consent to obtain information as opposed to the consent to provide information.

Paul Egerman – eScription – CEO
And it's an interesting question, Wes, but it's not the question we're talking about here. This is simply consent to participate in an exchange. That's what this is; the question we are addressing. We can talk about Judy's. Judy has raised an interesting question. We can put that on the parking lot to talk about later.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Okay. So that's actually news to me, because I thought that the presence of an exchange in the middle was one of the things we were talking about, but not the whole realm of discussion.

Deven McGraw - Center for Democracy & Technology – Director
Part of that is about when you have a patient choice to participate in a particular exchange model where does that choice get exercised. Is it at the point of data contribution or is it at the point of data access? In other words, the data is in and where the permission gets operationalized is I, as your treating provider across the city, have to ask you if I can go to the HIE to get your data, for example.

So to some extent there are a lot of decisions that get made about sort of how the choice is operationalized, but if we stick to our fundamental principle rather than trying to micro-manage those decisions, which are likely to be slightly different in different places, even when the trigger factors are triggered and choice is, therefore, required. I just fear— I mean I understand the question that Judy is asking, but I guess my response would be it depends. I'm not sure that we want to set sort of one national way to do this.

M
Right.

Judy Faulkner – Epic Systems – Founder
Well, I agree with you, Deven, and I think you worded it much better than I did. Thank you very much for that. The thing is that what has surprised me as I've watched it is the concern people have for something

we would think is so trivial. That's why I was wondering whether we should bring it up, so we don't burden them by having their legal staff declare that things we didn't anticipate are going to have to be done. It would be burdensome.

Deven McGraw - Center for Democracy & Technology – Director
Yes. And to some extent, we won't be able to control that. Even if we were to say, Judy, this would be okay to do in paper or electronic, there are state laws out there that have the peculiarity of requiring paper based authorizations that we can't override. So some of this is just going to be messy in the implementation until the states take some action to clean up some of their laws, there is more clarity about what the laws actually require versus the way that people have been interpreting them. Unfortunately, as good of work as we're doing, we're not going to fix that.

Judy Faulkner – Epic Systems – Founder
I'm okay with that. I at least wanted to bring it up.

Deven McGraw - Center for Democracy & Technology – Director
Yes.

Paul Egerman – eScription – CEO
So are we all set with the answers for number five? Are we ready to go on to the next one?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Can I just get clarity? All of our discussion, way above all of the indents and bullets that we have here there is a super paragraph that says this is about exchange through a third party organization called an HIO.

Paul Egerman – eScription – CEO
That's correct.

Deven McGraw - Center for Democracy & Technology – Director
Well, it's about triggers.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
It's about the triggers, which really—

Paul Egerman – eScription – CEO
We don't have to think about any case where there is not a third party organization handling the data here.

Deven McGraw - Center for Democracy & Technology – Director
Well, I don't know that that's true necessarily because certainly, we have choice laws, for example, that apply regardless of the model, but it's a lot less complicated when the triggers aren't triggered, for lack of a better way to put it, and you've got the provider in control of disclosure decisions from his or her record versus in models where—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
See, I think that simplification falls apart once we get to the next question, but if we can at least corral it to say we're only talking about relationships through third party organizations then it will help with the next discussion.

Paul Egerman – eScription – CEO
Okay. Let's go on to the next discussion.

Deven McGraw - Center for Democracy & Technology – Director
Okay. We've called this consent durability, but in essence, we've dealt with it in two ways in terms of our ... proposal answers. One addition that we put on the table is that consent should be revocable and such revocation should be prospective, forward acting versus retrospective and that information that is obtained by a provider consistent with the previous consent filed by the patient and maybe, I might say, once it's incorporated into that recipient provider's record it's treated the same as other information in the provider's record.

I hope that's self explanatory, but in case it's not, we had a lot of questions come up in previous experience of workgroup, actually, the one under the Busch administration where people thought if I obtain information from an HIE for which I have consent I have to treat it somehow separately once it's in my record from other information that I self generated. And so the principle that I put forth here is one that we have previously articulated and maybe we're stating again, which is that once you've obtained information, used it to treat a patient and it's become part of your record it's part of your record.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes, I would say that's a no-brainer. Absolutely.

M
I think this is perfect.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
But I think there's one use case – you've covered the revocability of the consent to contribute the data and you said it's prospective. You've covered the issue of what to do once the data has actually been consumed, but what about the case of data that has been contributed, but not yet consumed, so it's sitting in the HIE. You've withdrawn your forward facing consent. No one has accessed it yet. Do you have a right to get it out of the HIE?

Deven McGraw - Center for Democracy & Technology – Director
Good question.

M
And we haven't discussed anything about whether the HIE can provide it yet under that circumstance.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes. We haven't talked about it—

M
We specifically were instructed not to discuss that point so far.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
This is probably another point we're not supposed to discuss, but if we ultimately land on the opt-out model then I think that it should be retrospective as well because if they opt out of having their sensitive information out there, I'm sorry, somebody is going to have to go out and clean it all up.

Paul Egerman – eScription – CEO
Well, let's do it one step at a time. I think what Deven is saying is sort of like once somebody has given consent and the provider has used the information in the record it still stays in the record. The providers can't take that. They just can't do it.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Right.

Paul Egerman – eScription – CEO
They use that information to make a decision. You've got to keep that in the record.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Right.

M
Yes. Absolutely.

Paul Egerman – eScription – CEO
The more fundamental question, I think, is the one that David is asking. Let's say you have a situation where, according to the triggers we think there are triggers; an intermediary has control of the data or the intermediary has copies of the data and now the patient changes their choice, regardless of whether it's opt-in or opt-out; they change their mind. What does that intermediary do with their data that they have or do they delete it?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
... would be the assumption until you get the opt-out is an opt-in, so I want to make sure that if we land on the opt-out as a choice that they do have to remove the data from the HIO.

Paul Egerman – eScription – CEO
Okay. I think it actually doesn't matter whether it's opt-in or opt-out, because under either model the patient could change their mind.

M
Yes. I agree. I don't think it matters.

Paul Egerman – eScription – CEO
Yes, so if they opted in they could change their mind and say, "I don't want to do it."

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes, but look at bullet one, okay? I would accept that for changing their mind. I would not accept that for an opt-out model. For an opt-out model I want them to go back and take the information out of the repository.

W
But why isn't that the same thing you want done? It's, in essence, a revocation. The only difference between opt-in or opt-out is the default.

Paul Egerman – eScription – CEO
Right.

W
So once—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Number one, let me give you the scenario. If my genetic information is sent to an HIE before I say, before I'm giving an opportunity even to opt-out, the information is out there—

Paul Egerman – eScription – CEO
Wait a second. If I could interrupt you, Dixie? The assumption through all of this discussion is that all of the parties are playing according to the procedures that we put forward so that whether it's opt-in or opt-out you were supposed to have been told in advance.

W
But irregardless— Okay. I mean it's good to correct that, but let's say under Dixie's model you didn't opt out or you opted in and your genetic information went into the HIO. The next day, two weeks later, a year later you say, "I revoke. I don't want this any more." Then prospective, from that point forward where you pulled the trigger, speaking of triggers, and say, "I'm done. I don't want it any more," then it's not sharable.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I ... understand that. I don't think I'm communicating this well. Can I just try once more?

W
Okay. Go ahead, Dixie.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Okay. We have a situation where my information, before I even get a chance to give any kind of opt-in or opt-out, I haven't had the chance yet and before I have a chance, because we have an opt-out model, my information is sent out to a database. The next day I go into my appointment and I'm given this sheet of paper and I say, "Opt-out." Okay?

Now, if it were an opt-in model they couldn't have sent it to begin with, but with an opt-out model they could send it ahead of time because I hadn't opted out yet. So I'm saying that I don't agree with a prospective model if the consent is given as an opt-out because I believe if the consent is given to opt-out and the information is already there it should not just be prospective. It should be retrospective as well.

M
I think we're really discussing a couple of points here. One is the difference between giving it to an HIO and having it have found its way to another provider through the HIO, whenever the information has found its way to another provider and they've incorporated it in the record it's a done deal.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Right.

M
All right. Now, the question—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I'm talking the repository—

M
Right. I understand that. All right. So the question now, one that we've been deferring is what is the impact of a change to consent or if it's an opt-out model and someone has never opted out? Then the first time they opt out that is a change to consent. What is the impact of a change to consent on information that is still in the source database or in a shared resource database?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes. I think—

M
I believe when you say it's prospective you're saying from that point forward it can't come out of either one of those databases in response to a query. Then there's a further question, which, if I didn't raise it Gayle would, which is should it then be purged from the central database if it exists there.

M
And who's responsibility? I think that's an underlying important question.

M
Right.

Paul Egerman – eScription – CEO
Well, first of all, the concept ... revoke ...

Deven McGraw - Center for Democracy & Technology – Director
Paul, we can't hear you again.

Paul Egerman – eScription – CEO
For this concept that it's revocable in prospective, I had understood that to mean once you revoke it everything going forward has to follow your new instructions.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes. I agree with that.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yes. That's the definition of everything going forward I think—

Paul Egerman – eScription – CEO
Everything going forward follows the new instructions.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yes, but what does that mean?

Paul Egerman – eScription – CEO
The question that you're asking now, Wes, is what was written at the last bullet here, which is a question David had asked. I think instead of writing it as a question we probably just need to put it as a statement to get rid of the word does ... HIO that retains data has to return that information—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
What does that mean return it?

Paul Egerman – eScription – CEO
Return or destroy, whatever—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Destroy. Yes.

Paul Egerman – eScription – CEO
... has to destroy that information.

M
I used purge, but—

Paul Egerman – eScription – CEO
Purge. Whatever the right word is.

M
Yes.

Paul Egerman – eScription – CEO
That information, if the consent is revoked we have to think about this in terms of—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
That's the bullet that I was talking about.

Paul Egerman – eScription – CEO
Yes.

M
Yes.

Paul Egerman – eScription – CEO
So that's what we want. Then I think you need to expand it a little bit, because we have to think through the things. There are situations where the HIO has control of the data without having retention of the data. So we have to say similarly if an HIO has control and the consent is revoked they have to—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Paul, I think we also have to distinguish between two cases here. The same thing may be said a different way, which is that when a patient tells a provider they want to opt out or they want to revoke their previous opt in, is that for the relationship between that provider and the HIO or is that for the entire HIO.

M
I think we're saying it's just the provider.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Well, that's been my assumption, which means we have other questions to ask.

M
We have other questions to ask. I agree.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
So I mean if you take just the provider assumption then a patient who has decided to change their consent literally has to visit all of or at least call all of the providers they have dealt with in order to effectively revoke their consent.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes.

Paul Egerman – eScription – CEO
Either that or they have to contact the HIO.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Well, now we're assuming that there is a patient relationship with the HIO, which I didn't know that was an assumption we wanted to make.

Deven McGraw - Center for Democracy & Technology – Director
Yes. I mean I think getting back to our default that the fundamental ... of trust and exchange being with the provider and the patient that ultimately, unless the providers have made other arrangements to ensure that patient preference can be honored, that it would need to be done on a provider-by-provider basis.

Paul Egerman – eScription – CEO
I think that makes sense although, as I think about it, Wes, there are other analogies for that. If the patient gets a new job or gets new insurance they've got to contact every provider. That's just the way the system works.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
No they don't. I mean I don't ever tell a surgeon that did my surgery four years ago that I've got a new provider.

M
I think—

Paul Egerman – eScription – CEO
You don't need to tell them about the consent thing ... I guess you do—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I mean right now, frankly, I don't care that much, but would I if I had mental health information and I had stopped seeing a clinical psychologist two years ago, would I want to have to go back to contact them when they may have changed their business and everything to change my consent?

W
Yes.

Paul Egerman – eScription – CEO
I don't think we can get away with not requiring that the HIO be responsive to the consumer, because the providers may go out of business. They may sell their practice. They may just refuse to talk to you. You have to be able to go to the HIO—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I think that somehow we have to get the notion that when a provider participates in an HIO they are responsible for expressing the patient's consent to the HIO where it's implemented.

Paul Egerman – eScription – CEO
But only for the data they contribute. They don't know what else is going on. How can they be responsible for that?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Because they can say, "I have talked to this patient. This patient doesn't want their domestic violence information shared." All right? Or, "I've talked to this patient. This patient has revoked all sharing." As long as the patient understands that's what they're doing they can say that.

Paul Egerman – eScription – CEO
But that's back to my question of how does the patient manage access to the shared data—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
That's my—

Paul Egerman – eScription – CEO
... through the provider or through the HIO—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I'm taking a position here, which is that the patient, in having this discussion with the physician, is having it under the understanding that's relative to an HIO and they can express their preference for consent, their choice to that physician and have the physician responsible for conveying that to the HIO, but it's implemented across the board for the patient at the HIO.

Now, the physician is also responsible for limiting their future contributions of data—

Paul Egerman – eScription – CEO
Does that mean that every physician has to have the power to manage every consent for any possible sharable data that's accumulated in the HIO? That ... an impossible burden.

M
I'm peaking ahead at the NCVHS letter and saying at least for the constraints that they put on it this would be feasible.

Deven McGraw - Center for Democracy & Technology – Director
In listening to this conversation I'm trying to see if I can try to capture it here, which is that we acknowledge that in cases of where there are exchange entities that include the trigger factors that we identified earlier where it might actually be easier if the HIO were to provide the supported function to implement a revocation in a manner that goes beyond just the one physician or hospital record ... HIO should provide physicians with support in implementing revocation and physicians are responsible for their own data.

Carl Dvorak – Epic Systems – EVP
I think we're also going to have to factor in the complexities of physicians that move practices, merge, get acquired, split from practices where they both keep a copy of the records; the doctor leaving takes a copy and the organization keeps a copy where it was a group practice or something.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
There also might be cases of tele-consultation, other types of physician services that might be provided where there is no patient contact. Pathology and things like that that might occur on an outpatient basis or the language may, again, cause the record to be contributed to in some factor and how do we handle that, as well as how do we deal with revocation on that.

Paul Egerman – eScription – CEO
Well, John, those examples are ordered by somebody, right? If you've got a pathology test or a radiology exam that's ordered by somebody ... the person that's going to be responsible for submitting it to the HIE. It's not going to be the pathologist.

M
So the specialists aren't responsible for submitting their reports to the HIE? It's got to go back to the—

Paul Egerman – eScription – CEO
The specialists have a relationship with the patients, I would assume—

M
So the pathologist is not responsible for—

Paul Egerman – eScription – CEO
Yes. I think if a pathologist is responding to an order the pathologist isn't the one who submits it unless there's a ... that tells you to.

M
This might be a bad example, but I think when we look at tele-pathology – not tele-pathology, but other types of tele medicine, as well as consultation that might occur, I would think that there would be instances where there will be; I hate to use the HIPAA term; an indirect treatment relationship established, but I guess that's the only way to describe it. I mean—

W
I want to—

(Overlapping voices.)

Deven McGraw - Center for Democracy & Technology – Director
... not to try to answer every possible permutation that might arise in this space and to stick to some over arching recommendations that are true to our fundamental principle of the doctor/hospital/patient relationship, but understanding that in some of the models and particularly where the triggers are present, there are going to be some deviations from the norm that are going to have to be operationalized differently and consistently with the way the data sharing occurs in those models. So—

M
I definitely appreciate that, Deven, but I still think when you have a patient with a very complex record where they might have interactions with 10 or 15 providers and, as Carl Dvorak said, something may not even be around any more, there has to be some vehicle by which a patient, if they've made a decision to opt out, that that's handled in some other fashion other than having to track down providers.

Paul Egerman – eScription – CEO

Well, yes, but that's what she's got here because if the HIO is providing the physician and the patient with support in implementing their revocations they can do this, because remember, revocations have two parts to them. One part is to delete the data if there's data to be deleted, but the other part is to make sure nothing is happening prospectively. If the physician is no longer in business you don't have to worry about them doing anything going forward.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Right.

M
... clarity around that last bullet. I understand these are high level bullets, but that last bullet needs to be clarified a little bit and I'm not sure how.

Deven McGraw - Center for Democracy & Technology – Director
Well, you can think about how you want to make that clear, but this is not the final answer under that game show, whose name is escaping me. But the concept that I'm trying to ... here is this notion that, again, if a patient wanted to do, "I hate the HIO. I want out of it. All of it's gone," the HIO should be able to provide some support for that where the patient has made a clear choice.

M
I appreciate that. I think that's all I'm trying to say.

Paul Egerman – eScription – CEO
Okay. We have now modified one of our fundamental principles. We are now saying that there are situations where the patient must express their information with the HIO.

M
That would express situations where the patient can if they want to.

M
I don't know I just heard—

Deven McGraw - Center for Democracy & Technology – Director
Yes. Well, then you herd more than I intended. I would argue" - hood point, Wes, that if a physician says, "No. I don't mess with the data I give you unless I tell you. That's what the menace then, in essence there would have to be some negotiation there –

Paul Egerman – eScription – CEO
Yes. I think we're getting to a fundamental point that we have to make clear here, which is whether the relationship between the physician and the HIO includes any control over the data that can't be overridden by the patient on a global basis. I mean I think, as a practical matter, if there is any scenario, including an ability to contact the provider under which data goes and could be held in a repository and there would no longer be a mechanism for the patient to change their consent with that. Any scenario that allows that is a weakness in obtaining patient trust. Therefore, I think there need to be a mechanism by which the patient can express their current prospective consent at any time independent of the source of the data.

Now, I don't have any problem with saying that they must be able to express that through a provider and that they also may be able to do that directly with the HIO, but I think that the fundamental principle is that there is no loop hole where data goes into the database and there's no way to get it out.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I do think that that raises some interesting and technically challenging issues around the notion that if a provider is responsible for his or her own contributions only then withdrawing a sliver of the data is not going to necessarily be technically easy to do. Where I'm headed with this is what some HIOs do is build summary records that reflect if multiple providers are contributing CCDs, the HIO may build a summary that says here is a cross provider view of the current active allergies, the current known allergies to the current active medications. The data gets merged from multiple providers. Many providers may, in fact, say the same thing. The summary records shows the summary. It's not going to be easy to tease that out and pull out a sliver and say, "Oh, I know this data element came from that provider. It's been revoked."

Paul Egerman – eScription – CEO
That's not how you would implement it. I don't think—

David McCallie – Cerner Corporation – Vice President of Medical Informatics
That's absolutely how they're being built.

Paul Egerman – eScription – CEO
That's how they're built, but that's not how you'd implement the relocation, but I don't think we need to dive into that much technical detail.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
No. The point I want to make by that is that I think once the data is in the sharing entity, even when you've told the provider to turn off the spigot, the consumer still needs to be able to interact with that entity and say, "I don't want this shared any further."

W
I actually don't see it that way. I want to—

Paul Egerman – eScription – CEO
How could that—

W
I just want to say two things. One is that in the promises revocation I think a need to say that we will be able to, obviously, as Paul said, revoke any information we may be submitting prospectively and also say that while we can also request that any information that you now don't want to share be purged, there are limitations in what can be done. In other words, I think the consumer has to understand that once they agree to have their information shared and 17 different providers have access to it that I like the language of the provider helping the consumer to implement the revocation. But in the example that you give, David, I also think there's a limitation that we have to sort of implement, which is to say in that model where there is centralization and co-mingling of data from multiple providers it's kind of an all-in or all-out. If you want to revoke your consent and you go to your primary care provider and say, "I don't want information being shared," it has to be that fine, you can get out of that and all of your information is out, not just the immunization record that the primary care provider provided. In other words, you get out of the whole thing. I mean—

Paul Egerman – eScription – CEO
No, I don't—

W
Let me just finish.

Paul Egerman – eScription – CEO
Okay.

W
There has to be some real world constraints on revocation giving the consumer the option to say, "I don't want to do this any more." It may be because the consumer is concerned about a particular part of their data and maybe because they're concerned about all of it and they don't want it to be shared. I think, depending on the model, that revocation takes on a different flavor, whether the data is stored, whether it's co-mingled with other things, all of these things we said triggers higher and higher levels of risk and higher and higher levels of privacy and security concerns. If a consumer wants to say to their primary care provider, "I don't want your information to be shared," I think it is okay to say we just want you to understand that all of your information from contributing providers will be purged.

W
Yes.

Paul Egerman – eScription – CEO
Yes, but I think we are capable of building systems that allow more control than that. It doesn't have to be all or none, but my point is that the HIE must provide some tools for the consumer to manage this if they wish to take that level of control. It can't strictly be on the provider that the consumer has to go to every provider they've ever seen and ask them to revoke the data. I just think that's unfeasible.

W
I'm explaining why that's not necessary and why if the consumer talks to their primary care physician in a model like the one that you're describing and says, "I don't want to participate," the provider on the part of the consumer can implement that revocation completely.

M
That's right. So what I hear is—

M
... that. Wes, summarized it. I just didn't follow.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Well, it might help me to understand if I summarize it and, Carol, tell me if I got it right, but we are agreeing that when someone gives consent to a physician they may have some categorical control on the data that the physician releases on a prospective basis. We haven't discussed that yet, but it's on the agenda. We are agreeing that a patient should be able to express through a single entity either their physician, always their physician and sometimes directly with the HIO the ability to withdraw a consent that was given past.

We agree that implies that the data will no longer be sent to any inquiring provider. We seem to be discussing the specific point of the complexity of having the patient modify their categorical consent and Carol has suggested, and I think I agree, that we can create the limitation that if people want to withdraw consent it has to be non-categorical.

Paul Egerman – eScription – CEO

I would not agree with those statements.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Wait. Wait. Wait. Before you respond to Wes' statement and my statement let me correct it a little bit and to say that there are certain models where the withdrawal of consent can be non-categorical. The model that you suggested, which is where data is not only stored centrally, but it is co-mingled with data for multiple providers may trigger that kind of non-categorical withdrawal. I would hope that there are other models where both data is not stored centrally or where there is more granular control available because there isn't a central co-mingling of data from multiple providers in a permanent storage where other kinds of revocation were categorical can be implemented.

Paul Egerman – eScription – CEO
Yes. Yes.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
I'm just saying there are different flavors on the table.

M
So if I can? What you're saying is there may be cases where HIOs have to restrict revocation of consent to non-categorical, but we'd like to see it be better than that, which, in sort of my program terms means that they're generating a summary. They're doing it dynamically rather than statically.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Yes. I actually think this discussion is a good example of why we can't go into the detail, detail, detail of every single technical model. We can use these over arching recommendations to try to point people in a direction that we think is good from a privacy and security standpoint and hope that it gets implemented in a way that's good from a privacy and security standpoint, but I worry when we start getting into the ways people are implementing it and all of the different variations that we miss the opportunity to do our job, which is to make the kinds of recommendations that, both, impact the way ... implemented and also the way technology is implemented.

Paul Egerman – eScription – CEO
Those are excellent comments, Carol, because we also are running a fair amount behind schedule because we have some very interesting things we need to talk about about sensitive data and so excellent comments. I appreciate that.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Can we at least fix that third bullet consistent with what Carol just said? Because I agree with her too.

Paul Egerman – eScription – CEO
Isn't it consistent?

Deven McGraw - Center for Democracy & Technology – Director
I tried to, Dixie—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Pardon?

Deven McGraw - Center for Democracy & Technology – Director
I tried to. Is it not quite there yet?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
No. Her point about, first of all, consumer needs to understand where limits to categorical ... in certain models and such as ... should be deleted, I believe. Do you agree, Carol?

Deven McGraw - Center for Democracy & Technology – Director
Okay.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
That's fine.

Deven McGraw - Center for Democracy & Technology – Director
Yes. I'm actually suggesting that the policy recommendation shouldn't now sort of delve into every particular model. I think what we want to say from a policy standpoint in this bullet is that they have the responsibility to implement revocation. We don't have the responsibility to figure out every possible nuance of implementation of HIE, what that revocation necessarily looks like.

(Overlapping voices.)

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I just have to say that if the implication of what Carol is saying is at the end the statement should be clean I'm fine with it. If the implication is we shouldn't be testing these ideas against models that we understand exist then I think in our conversation I think that's a really—

Deven McGraw - Center for Democracy & Technology – Director
No. I think the trusting, Wes, is really important. I'm just suggesting that we can't possibly delve into the kinds of recommendations that then granular about every particular model that's out there.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yes. We need to boil it back up to a clean top-down, bottom-up, top-down kind of approach then.

Carl Dvorak – Epic Systems – EVP
I do think we need to factor in the notion that the future requirements under meaningful use are really going to require discreet data to flow back and forth in the provider's records. The patient is going to be very unlikely able to figure out where the data went after the first provider disclosed it, because that data will be incorporated in other people's records I think as we think about policy we do have to make sure it's implementable.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yes, but I think the assumption I'm working under is that we're talking about the constraints on the HIO in terms of enabling a provider to get data. They might provide it from a central database. They might provide it through some HIE-like mechanism where it goes back to an original repository, but we're not talking about the flow of data end-to-end and then end-to-end, because some of that will be implemented to directed exchange, some of it will be implemented through HIO kinds of exchanges. It's just a separate topic.

Paul Egerman – eScription – CEO
These are excellent conversations, but I'm really looking forward to starting that sensitive data discussion because that's going to be something where we've all got to fasten our seatbelts. It's going to be an interesting discussion.

Deven McGraw - Center for Democracy & Technology – Director
It's all been a fastened seatbelt discussion. I think I've got the crux of the recommendations captured here and so I would propose that we move on. I'm also happy to ... them so we don't continue to spend time wordsmithing them on the call.

W
Deven, I would suggest on the third bullet to take out the wording in brackets. I mean I think that was instructed for our conversation, but I don't think that need to be explicit about what it means for different models. I think we want to, at a policy level, stay at the level of whatever you do you have to be able to implement a revocation.

Paul Egerman – eScription – CEO
Yes.

Deven McGraw - Center for Democracy & Technology – Director
Okay. Sounds good.

Paul Egerman – eScription – CEO
That does sound good. So, as soon as Deven finishes her—

Deven McGraw - Center for Democracy & Technology – Director
Yes, we can go back. I can relinquish control.

Paul Egerman – eScription – CEO
Yes. This is like a huge transition here of control. So the control of the slide presentation has now been relinquished by Deven.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
So did she give you consent or—

Paul Egerman – eScription – CEO
That's actually between me and my attorney.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Okay.

Paul Egerman – eScription – CEO
The next item we had on the agenda was—

Joy Pritts – ONC – Chief Privacy Officer
I just want to make sure I understand something. So at the end of the day this recommendation is essentially saying; and I'm trying to clarify it because I'm sure that others would want this answer as well; this recommendation is essentially saying that an individual would need to, if the factors, any of the factors that we talked about were triggered an individual would need to provide consent to every provider to participate in the health information exchange. Is that right?

Paul Egerman – eScription – CEO
That's correct.

Deven McGraw - Center for Democracy & Technology – Director
Yes. I think, Joy, it's important to clarify we're saying basically the permission is not so much the health information exchange at the high level, but it is the participation of the provider's data, the data that that provider holds.

Joy Pritts – ONC – Chief Privacy Officer
Right.

Deven McGraw - Center for Democracy & Technology – Director
Can I ask the person who's typing to mute? Thank you.

Paul Egerman – eScription – CEO
I'm sorry, Joy. Did you get your question answered?

Joy Pritts – ONC – Chief Privacy Officer
Yes.

Paul Egerman – eScription – CEO
Okay. ... ask the question, are you comfortable with it? Do you have an issue with it?

Joy Pritts – ONC – Chief Privacy Officer
I think there will be people who do have an issue with it. I think it is ... to several of the models that are out there and that there will be people who have issues with it, but I wanted to clarify that that's exactly what you meant. It sounded like you had considered those other options to get to that.

Paul Egerman – eScription – CEO
Thank you. Are we ready then to move on to John and Leslie, who are going to give us a little update on NCVHS?

Deven McGraw - Center for Democracy & Technology – Director
I think we are.

Paul Egerman – eScription – CEO
Great.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
This is Leslie. ... the slide ...?

Deven McGraw - Center for Democracy & Technology – Director
Yes. They should be up.

Paul Egerman – eScription – CEO
They're on the screen right now.

Deven McGraw - Center for Democracy & Technology – Director
It's a different format, Leslie. That's all.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Are you driving, Leslie.

Deven McGraw - Center for Democracy & Technology – Director
No, they are at Altarum. You just need to let them know or you can tell me. Only Paul and I and Altarum has the ability to drive slides.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I'm talking about driving the conversation.

Deven McGraw - Center for Democracy & Technology – Director
Oh.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
John, you can start. All I wanted to say was that the slides that I gave indicate a summary of the prior NCVHS recommendations, a list of the sensitive categories that we're currently considering commenting on; I'll put it that way; or delineating and third, a list of some cross cutting issues with respect to sensitive information and system architecture. We're not planning in the letter to address those architecture issues. I just tried to send those around to be informative for people—

(Overlapping voices.)

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Now I'll turn it over to John.

Deven McGraw - Center for Democracy & Technology – Director
They're up for the call, but we did not distribute them in advance.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Okay.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Okay.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Why don't we just go through this briefly. Leslie, we can tag-team however we need to in this. As a matter of a little bit of background, I think if you go back to the NCVHS Web site or if you have a hard copy, there was a recommendation letter that was sent on February 20, 2008 that was titled *Individual Control of Sensitive Health Information Accessible by the Nation Wide Health Information Network for Purposes of Treatment*. These are really where – I believe this is where ..., Leslie?

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Yes. That was the initial sensitive information letter.

Deven McGraw - Center for Democracy & Technology – Director
Yes, and people did get that.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Right. Yes. The recommendations that I put on the first couple of slides are copied directly from that letter.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Right, so—

Joy Pritts – ONC – Chief Privacy Officer
Leslie, this is Joy. I think that before we jump in here I'm going to be very specific about what I ask here, okay? I think the group needs to know what your general recommendation was on the consent issue, because it varies from where this group ended up, I believe. I don't want another discussion of whether that's appropriate or anything like that, but I think that it's important to know that if we get into the sensitive information.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
I'm puzzled a little by your question, by your comment.

Joy Pritts – ONC – Chief Privacy Officer
NCVHS made a general recommendation about whether individuals should have a choice of participating in health information exchange, right?

Deven McGraw - Center for Democracy & Technology – Director
It was about the NHIN.

Joy Pritts – ONC – Chief Privacy Officer
About the NHIN?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Yes and it was specific to sensitive information.

Deven McGraw - Center for Democracy & Technology – Director
Yes.

Joy Pritts – ONC – Chief Privacy Officer
All right. I don't have mine up yet. You had the recommendations for sensitive information came in conjunction with a general recommendation though, that people had some choice to participate in NHIN, right?

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
It followed on, I believe it's a 2005—

Joy Pritts – ONC – Chief Privacy Officer
Right.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Which is before my time on NCVHS.

Joy Pritts – ONC – Chief Privacy Officer
Okay. So—

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I was around during that. Some of the recommendations that come from that prior report though are; and I'll read them off to you, because they don't necessarily go completely to opt-in versus opt-out, but one of the recommendations was, by example, HHS should assess desirability and feasibility of allowing individuals to control access to the specific content of the health record via the NHIN and if so, by what appropriate means. Decisions about whether individuals should have this right should be based on an open, transparent and public process.

Another one is if individuals are given the rights to control access to specific content on the record by the NHIN the rights should be limited, such as based on being based on the age of information, the nature of the condition or treatment or type of provider. Those, I think, probably go to your question, Joy.

Joy Pritts – ONC – Chief Privacy Officer
Yes. Thank you.

Paul Egerman – eScription – CEO
Although those are all, as I understood it, sort of like, when you say control content, I understood it as like segmentation kinds of things. It's like after you're already in the NHIN can you control what the content is that is exposed.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Well, I think if you go back to when these recommendations were made, I don't think there was, frankly, much understanding of the nature of how the NHIN was going to be structured—

W
Yes.

W
Yes.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
And honestly, it's been four years since I was involved in these discussions. I apologize. I have a really horrible memory any more, but I think we tried to stay away from, as I recollect, the idea of opt-in versus opt-out, but I haven't looked at our recommendations.

Paul Egerman – eScription – CEO
That's correct, although the comment I wanted to make was that if I remember it right it was the 2006 letter—

W
That's correct.

Paul Egerman – eScription – CEO
Basically it had a sentence in it where it says the two most difficult and contentious issues are whether or not to participate and if you participate, whether or not you can control the content or how—

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
That's exactly right. That's what it says. Yes. I've got the letter up actually.

Paul Egerman – eScription – CEO
And so in some sense that's entirely consistent with what we're saying, because we basically so far have answered the first one about participation and now we're about to answer the second one, which is the content and the participation.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Actually, just to follow up on Joy, here is what the recommendation actually said in that 2006 letter. "Individuals should have the right to decide whether they want to have their personally identifiable,

electronic records available via the NHIN and then HHS should monitor the development of opt-in/opt-out approaches, consider local and regional and provider variation, collect evidence on and continue to evaluate in an open, transparent and public process whether an opt-in or opt-out is appropriate."

Joy Pritts – ONC – Chief Privacy Officer
Thank you.

Paul Egerman – eScription – CEO
So I think, Joy, that we are completely consistent so far.

Joy Pritts – ONC – Chief Privacy Officer
Okay. Thank you. But it's good to have that as a background before we start this discussion.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Yes. We ... consensus and basically ponder the issue not knowing. I think we purposely punted that issue.

Paul Egerman – eScription – CEO
You were smart.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Then there also was, for example, ... says role based access should be employed as a means to limit the PHI acceptable via the NHIN and R-9 HHS should investigate the feasibility of applying contextual access criteria, support, research and technology to develop contextual access criteria, etc. So my read is, frankly, the way at this point I would take the 2006 letter is that it identified the issues for follow-up more than concluding one way or the other on some of the kinds of questions that you all have now been talking about.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
That is absolutely the case. Yes.

Deven McGraw - Center for Democracy & Technology – Director
Very helpful. Thank you.

Joy Pritts – ONC – Chief Privacy Officer
That was very well said. Thank you.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Yes. So with respect to the last letter or the letter we're going to talk about today, which is related to sensitive information in the NHIN, there were some recommendations that were made that have been outlined on about five slides that Leslie put together. Do you want me to read through them? Is it meaningful to do that? How should we go about this?

Deven McGraw - Center for Democracy & Technology – Director
Is there a way to summarize them?

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Well, can people just get them off? It wouldn't be hard?

Deven McGraw - Center for Democracy & Technology – Director

What do you mean, e-mail that to everybody? Because I didn't get it.

M
We all got the letter and these are in the letter, right?

Deven McGraw - Center for Democracy & Technology – Director
Yes. They're all in the letter. Everybody got the letter. The slides, to the extent they're ... the letter, they're now up on the screen. I'm not understanding how people don't have this.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
I copied them directly from the letter, so I could just read them.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Do we need them read or do we need to discuss them in order? I think let's just read through them very quickly.

Deven McGraw - Center for Democracy & Technology – Director
That's fine.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Do you want me to do that, Leslie, or do you want to do it?

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Sure. You can go ahead and do it. I don't have them up yet.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
All right. 1A: The design of the NHIN should permit individuals to sequester specific sections of their health record in one or more pre-defined categories. The list of potentially sensitive categories and their content should be defined on a national basis so that it is uniform across the NHIN. Just to telegraph that, that is one of the things we're trying to do now is NCVHA is trying to help establish the sensitive categories.

1B: HHS should initiate an open, transparent and public process to identify the possible categories of sensitive information for sequestration by individuals and to define with specificity the criteria for inclusion and exclusion within each category. The process should take into account both patient concerns about privacy and concerns of healthcare providers about quality of care. Again, that's what I think NCVHS is doing right now, as we speak.

1C: The design of the NHIN should ensure that when a healthcare provider accesses health information with one or more categories sequestered, a notation indicates that sensitive health information has been sequestered at the direction of the patient. The specificity of this notation will need to be determined.

1D: The design of the NHIN should permit individuals to authorize selective healthcare providers to access sequestered health information.

We could talk about any of those now or do we want to go forward and go through the rest of the recommendations?

Deven McGraw - Center for Democracy & Technology – Director
Why don't you do them all and then—

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
We can go back?

Deven McGraw - Center for Democracy & Technology – Director
Yes.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Okay. Can we go on to the next slide then, please?

Paul Egerman – eScription – CEO
Just to be clear, John, this is a recommendation that you already made in 2009?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
That's correct.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
That's correct. Those are copied directly from the letter.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
These are ... actually, the end of 2008 I think was when the letter went out.

The next recommendation, 1E: The design of the NHIN should contain a break-the-glass feature enabling healthcare providers to access an individual's complete health information, including sequestered information, in the event of medical emergency.

1F: The design of the NHIN should provide that if a healthcare provider obtains emergency access to sequestered information a description of the circumstances surrounding access are made part of the audit trail and the healthcare entity designated privacy official is notified automatically.

1G: The design in NHIN should provide that if a healthcare provider obtains emergency access to sequestered health information the patient or the patient's representative is notified promptly.

1H: If a healthcare provider obtains access to sequestered health information the provider is responsible for taking whatever action is required to continue to protect the stated privacy preferences on the patient.

Next page, some other recommendations, recommendation two: HHS should monitor developments in a relationship between clinical decision support and sequestered health information and determine if or when pilot projects, trial implementations or other research measures are warranted.

Recommendation three: HHS should support research, development and pilot testing of technologies and tools for sequestering designated categories of sensitive information transmitted by the NHIN.

Recommendation four: HHS should support research, development and pilot testing of public and professional education programs, including informed consent needed to implement the sequestration of sensitive health information.

Recommendation five: HHS should support the ongoing study of the consequences of sequestration of sensitive health information, including potential liability issues, benefits and costs and human factors necessary for successful implementation.

I think those are the recommendations if I'm not mistaken. I think the first three slides were recommendations.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Yes. Those are the complete set of the recommendations from the 2008 letter.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
So maybe what we want to do is, before we go forward and talk about some of the other things in this presentation, maybe we want to spend a few minutes talking about these different recommendations that were already made.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Yes. I vote for that. This is Carol.

Deven McGraw - Center for Democracy & Technology – Director
Yes. That's fine. That's fine. Can you tell me, John, what you meant by the term sequestration?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Sequestration. Again, part of the dilemma we had with writing some of these letters is not understanding fully the architecture of NHIN. To the extent there is information that's housed within an NHIN, meaning it wasn't simply a transport mechanism, if there was data that would be part of an NHIN, that sequestration would be if there was a sensitive category of information, let's just say psychiatric information or other information that the patient desired to have kept confidential, that that data would not generally be made available to individuals, who might be querying for information in the NHIN and that if somebody queried for information in NHIN and there was sequestered information as part of a patient record, that at most what they would see is the fact that there was sequestered information that might be available or that might not be otherwise provided to that provider upon querying.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
So what that effectively means is the capacity to separately identify and map—

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Restrict access and map. Yes.

Paul Egerman – eScription – CEO
So how is sequestration different from segmentation?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
It's probably really not any different. It's the notion of just keeping it private and not necessarily available to providers. Now, if you notice, one of the later recommendations also spoke of the fact that the advanced clinical decision support might require that sequestered information. That was recommendation number two. So we thought that there needed to be some type of monitoring of developments in that area because obviously, good clinical decision support could be affected by information that was sequestered and there's a lot of that that goes on today with respect to including that type of information, at least in local EHRs when clinical decision support rules fire.

W
Can somebody go back to the first set of recommendations? I have a macro comment to make and I definitely think this is an artifact of the historical nature of some of these recommendations, but I think it's

an important one to highlight. That is that all of these recommendations refer to NHIN as a noun, the NHIN. All of these recommendations bestow requirements for powers on that entity or that noun. I don't think that's necessarily the way that it's seen today. In other words, this is really about the parameters for health information sharing.

As NHIN is described today, the sort of standard policies and services that enable health information sharing over the Internet, it really makes you sort of understand that the direction that, at least we've been going in this group is, in some ways, going to address a lot of these issues because, for instance, even in 1A we have basically defined this issue by saying that the decision about what to share and how it's shared rests with the provider or the patient. It makes this look very historical, I guess I would say.

M
I don't know if there really is an architecture for the NHIN yet. That's my only concern is I think it does seem to start to appear historical, but do we really understand what the NHIN really is going to—

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
We have a working position on what it isn't.

Paul Egerman – eScription – CEO
You're asking an interesting question, because when we started our discussions there were a number of people; I think Carol was one; I think Latanya was another, who expressed concern that it's very hard for us to do good work without having a clear knowledge of the architecture of the NHIN.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
My view actually is not so much that it's hard to express views without knowing the architecture. It is that architecture can help to implement some of our policy objectives if it's viewed as a tool that can enhance privacy and security as opposed to trying to figure out the architecture and then saying, "Okay. What are all of the possible privacy and security permutations?" In other words, the way health information sharing gets implemented is also an opportunity to implement those approaches that are protective of privacy and security.

Paul Egerman – eScription – CEO
The more fundamental issue, rather than revisiting that issue, that Carol is raising, which is a good issue and may be partly what Joy was responding to too when she was asking how consistent we are with NCVHS is it's sort of like a terminology issue. You talk about the NHIN and we talk about information exchange. It's not entirely clear we're both talking about the same thing.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Let me say one thing here. I agree completely that the issues are inter-related in a lot of ways. I think that the concern that gave rise to 1A, if this was exchanges as well, whatever form they take, in the following form suppose, for example, that I consult with my—

Paul Egerman – eScription – CEO
I agree with that 100%.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
I'll just use the reproductive example. I talk with my reproductive health provider and we decide that, yes, it's important to have my reproductive history be included in the exchange, but at the same time, I don't want my reproductive history to be accessible to everyone who accesses my records in the exchange.

So I would still want a sequestration capacity potentially, even if in the consultation with my provider I wanted the information to be generally accessible and to travel through the exchange.

Paul Egerman – eScription – CEO
But now we're talking about granular consent, which is what I think sequestration is.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Let's just back up a little bit. Leslie's comment is a good one, which is it's sort of like whether we call it NHIN or whether we call it information exchange the point that they've made in their 1A recommendation is a valid point.

Paul Egerman – eScription – CEO
That's correct.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
So what we need to do is make sure we understand where NCVHS is in all of their recommendations, because otherwise we're getting lost. We need to have that as a foundation before we can start talking about some of this other stuff that we need to talk about in terms of ... data.

M
As a working discussion couldn't we just substitute health information exchange for NHIN throughout these and—

W
I think you could and one other thing I'd point out, which I think people thought was very important in the sensitive information discussion is some kind of uniformity because if people are dealing with records that come from all kinds of different places in an exchange and there are multiple meanings of sensitive categories it's going to be remarkably confusing.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I think that's a really important assumption, but I think it's a debatable one, because I don't want us to take it as a given that there are a discreet set of sensitive categories that everyone agrees about because I think sensitivity is highly contextual.

W
Yes. I totally agree with that. I don't think we can know what's sensitive for every person. I also think that the advantage of the approach that says the patient and the holder of their information make the decision about what and when and how to share it under whatever circumstances exist is a consistent approach, but it doesn't require sort of uniform agreement on what the sensitive conditions are.

Paul Egerman – eScription – CEO
So we're starting to ask you some questions, Leslie and John. Where are you? have you completed your presentation or was there more material you wanted to present to us?

(Overlapping voices.)

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
... sensitive issues. I think we started that conversation, but perhaps we need to look at those before we continue. This is Carol.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I'm confused. I misunderstood. We'll look at what?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
We need to define sensitive issues.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Do you want to do the next two slides, Leslie?

Paul Egerman – eScription – CEO
Yes.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Sure. So as NCVHS looked at sensitive categories, both in the 2008 letter and I apologize I got the date wrong when I was throwing these slides together yesterday and also with our more recent hearings, the categories that consistently were raised and that we heard testimony about, significant testimony, both in 2008 and then supplementary testimony in 2010 were domestic violence, genetic information, mental health information with the note that there's a specific sub-category ... psychotherapy notes as per HIPAA, reproductive health issues, including matters such as abortion history, the use of assisted reproductive technologies, sexually transmitted disease history and issues such as that, substance abuse and I'll drop the other footnote ... and special issues regarding records from children and adolescent issues, for example, such as the diagnosis of ADHD, sexual orientation discussions between an adolescent and a provider, adolescent sexual activity, adolescent drug use and so on.

W
Where would you put HIV in that?

W
The status of it doesn't ... into reproductive health ...

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Yes.

W
... on transfusions.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Sexually transmitted disease history.

(Overlapping voices.)

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
But you're right. A separate category could be HIV.

M
Leslie—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
... of deniable information that they came up with in, I guess, the mid '90s or so?

W
Viable information?

M
Deniable.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Around the mid '90s the Institute of Medicine came up with a list of what they called deniable information and these were protected information where if a person would appear at the hospital and say is Joe Schmoe here you could actually deny knowing anything about it. That's why they called it deniable.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
We did not take that into consideration.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
HIV/AIDS was one of them. Sexually transmitted diseases was another, so in many ways this is similar, but it's not exactly the same.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
This is not an exclusive list by any means, but these are the categories that we heard significant testimony about.

M
So you didn't hear testimony about genomic data?

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Yes we did.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Yes we did. Number two.

M
Oh. I'm sorry. I missed it. Okay. Yes.

Judy Faulkner – Epic Systems – Founder
If you look at something like mental health information and we're trying to think this through as for the EHR vendors who have to comply with it, did you talk about what might be suppressed within that?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Judy, you raise a really good point. Let me maybe describe before we go any further what the focus of our attention has been with regards to the upcoming sensitive information letter.

In order to get this letter completed we felt it was most efficient if we simply said, "Okay, we're going to help define what we believe to be sensitive categories of information and what information within those categories is considered sensitive." We did not and I don't believe we want to really go down the road of trying to architect how it should be sequestered or what should be sequestered or how it should be handled. We wanted to get out what we thought were the categories of information, what made them sensitive, what parts of that information was really sensitive. One of the things we did was we took testimony from some mental health experts in order to understand, like in the case of mental health, really not only what was sensitive, but what were the implications if that information is not available.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
I think if you want to just get a little bit more detail about what went on there, one of the underlying questions has been the extent to which primary care physicians ... providing them healthcare and so how do you try to figure out how to sequester from primary care records and so on. The most easily separable category of information there is, of course, separate psychotherapy notes that are kept separately anyway.

Another underlying set of questions is what about the availability of a diagnosis, because of the importance of that potentially to other care. What about prescription lists?

The reason for the next slide was just to identify some of the kinds of questions that might be over arching questions about, for example, whether you have a diagnosis of HIV, a diagnosis of depression or whatever. Somebody may need to know your medication list regardless of what's sequestered with respect to the particular diagnosis.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
One other category there that this first bullet actually brings to mind is that celebrity people, where their entire record ... sequestered.

M
Some of that discussion really has come up in the context of abuse, because it's very much the same issue. What do we need to do about people that simply their whole entire record needs to be in some way protected?

W
That's why I sent around, actually, a comment when you all were talking about the opt-in/opt-out general architecture question that suggested that one possibility to think about, whether you're thinking about opt-in or opt-out is opt-in with a flag to the entire record is sensitive or on the other side, opt-out with a flag to the entire record as sensitive.

Paul Egerman – eScription – CEO
We're not going to talk about that right now. I just want to make sure that we understand where things are right now. On the previous slide you show these roughly six sensitive categories. One question I have is to what extent are you providing additional definitions of these? If you look at the last one it says, "Information from children and adolescents." I assume that means information that you wouldn't consider sensitive if it appeared in an adult, but if it appears in a child or an adolescent you do consider it sensitive. But do you have a way to give us some further definition of that and list that out or is this the entire definition?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Recognize this: This is a very short summary. We are still working on the recommendations that we are going to bring forward for NCVHS to discuss and, I guess, vote on. This is not final. It's very preliminary and so there is a lot of detail behind this. We took a lot of testimony on this—

(Overlapping voices.)

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
I think the answer to the question is we are hoping to have further definition of these. That's part of the plan, but at this moment it would be preliminary for us to say we have that, because it hasn't—

Paul Egerman – eScription – CEO
Let me ask my question a little bit differently, because I understand there's a September letter that's going to happen—

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
We're hoping for that.

Paul Egerman – eScription – CEO
A rough guess of the time frame as to how we go from this to a point where it's definitely decided these are the six categories or the five or whatever they are and this is what's in them?

Christine Bechtel - National Partnership for Women & Families – VP
Hey, Paul, can I jump in and just ask another question so we can be efficient about the answer because it's related here? Which is to what extent you guys are considering how technology can play a role in fleshing some of this out, because it seems to me that having broad categories might be a little bit too blunt, because within categories that I think people are pointing out is that depending on the age of the information and the age of the patient, whether it's an acute condition versus a chronic condition, it seems to me the different logic rules can apply within those categories and that's a perfect role for technology to help facilitate and further sort of granularly define what is a piece of sensitive health information or a relevant sense of health information, particularly in a break-the-glass function.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Again, our desire here is because of the timing to try and get a letter out and the fact that we could argue those types of things for an extended period of time, we're looking at putting a letter out that provides guidance as to what we believe are sensitive information and why they're sensitive so that other people can then take that and decide based upon architectures and upon other considerations, how to manage that information in the context of an NHIN or in regional exchanges or EHRs even, so again, we are not overlaying a technology solution or technology recommendation at all on this. We're just trying to get the basic groundwork laid as to what is sensitive information.

M
So then if I can understand that, you haven't considered the feasibility of associating a specific report or other piece of information with the categories. Is that correct?

(Overlapping voices.)

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Let me say this again. The NCVHS has a limited capacity and we recognized that one of the things that needed to be done as a precursor to doing anything was to try to define what sensitive information is and why is it sensitive. There are a lot of people that are working on this that can take that then and can overlay on top of it, if you look at architectures and technologies and, frankly, other value judgments as to how it should be protected or not protected.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Let me give you a specific example of that. Genetic information, under the ... Act is defined to include both, genetic tests and certain family history information. Now, it might be quite easy to sequester, identify a test result and very hard to identify all of the family history information that's in a medical record—

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Or even the mention of a genetic test result in a dictated report. I mean it's—

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
You're right. It's very, very hard. So the question is on one hand we might be able to say this is a sensitive category. It really matters a lot to try to develop these identifying capacities technologically and have the tech folks come back and say we can do it, but only to this extent.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
It seems to me like David McCallie made a really insightful comment a while ago. Sensitivity is definitely contextual and it would seem to me that NCVHS would want to recommend that somebody develop an ontology that captures the context as well as the categories, both the concepts and the context and not just these lists of categories.

M
I'd like to suggest that we address the question of whether we think whatever categories we identify are stable or whether contextuality is likely to change fairly rapidly over time—

(Overlapping voices.)

M
Even before we get that, I was just trying to understand when they're going to finish defining the categories. I mean—

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Here is our proposed timetable and we're hoping to make it work. We have two subcommittee conference calls scheduled for August. We have a full day before the full committee meeting in September and our intent is to have a letter draft ready to come out of the subcommittee hopefully in our August conference call. Then we're going to send it around to the full committee to have them look at it and use some of the time to take it before the full committee meeting to respond to comments we've gotten from NCVHS committee members not on the subcommittee and then have a letter. There's time on the agenda for this, I believe it's September 17th, something like that, NCVHS meeting. The goal is to have a letter out then.

Paul Egerman – eScription – CEO
The goal is to have a letter out in September that defines the categories?

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
That defines a list of categories. It, of course, would not be regarded as a full list. When somebody says the contextual nature one thing I might add is there are some context points that are likely to be quite stable, for example, whether the record is the record of an adolescent or the record of an adult.

Paul Egerman – eScription – CEO
That's correct and so in September you have a letter and the letter is like our letters, it's a recommendation to the secretary?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Yes.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair

Correct.

Paul Egerman – eScription – CEO
But it only defines the categories. It doesn't give us any additional help or does it?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
No, it doesn't define the categories and hopefully we'll be able to overlay these particular pieces of information that might be considered in a category that really are sensitive and so it's just simply not listing how many categories. There is going to be some type of analysis or discussion behind each category and to try to describe the bounds of the sensitivity, as well as why it is sensitive.

Carl Dvorak – Epic Systems – EVP
One of the things I read in the NCVHS report was the notion that they felt it was important to have a single, nationally defined set of categories because of the educational requirements for both, providers and patients to be able to understand and implement it effectively.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
That's part of what we're trying to do here. But again, we're not trying to overlay the technology discussion, because we felt it was important to try to get this letter finalized so that others could use it for just that purpose.

Carl Dvorak – Epic Systems – EVP
Yes. I'm just trying to reinforce that I think. If this has a prayer of working it really would need to be a single, national list because the educational requirements are going to be very significant to help people organize their charts in a fashion where you really could implement this in a way that patients could rely on it.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Part of the recognition here is that it's going to be incredibly difficult to, in certain contexts, define what is sensitive. PCPs today handle everything. Frankly, I just found out there are new drugs that are approved for opiate abuse that are now to be prescribed by PCPs, as well as they handle depression and other types of minor psychiatric conditions. That data is typically within the PCP's record, the family practice provider. So It's not necessarily being delivered through some type of organization that you could look to then say that's sensitive information because it's coming from a psychiatric facility or drug and alcohol program.

Paul Egerman – eScription – CEO
In terms of timing, John or Leslie, I understand the letter is in September. Do you have any sense of what happens after that? Are there hearings or public comments? Do we have six months before rules come out?

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
We don't do rules.

Paul Egerman – eScription – CEO
Okay. I know you don't, but—

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
We give recommendations to the secretary that the secretary can either decide to or not to act upon. They can then turn something like this over to ONC. It really—

Paul Egerman – eScription – CEO
I see.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
Also, I might point out that part of what we've been trying to do is coordinate as carefully as we can with you so that we pick up where we've had experts ... we've had the hearings prior on designing categories. So trying to figure out who should be doing what so we're not each inventing different rules. I tried to list what I saw in the last slide as additional cross cutting architectural issues.

Paul Egerman – eScription – CEO
So we should give you a chance to go through that.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
They're not the only ones, but several of them have been brought up actually already today, such as the question of ... an entire record. What about breaking the glass features? How do you figure out how to really sequester if the glass has been broken? What about other kinds of transfers of data if a patient gets, if a record comes to be the record that's in any kind of repository and then there's a request to transfer it out rather than transferring records from a particular position and the adolescent architecture. I'm sure there are more of those architectural issues. Obviously, the what if you can't do it technologically problem. Any or all of those are ones that, for now I think it's fair to say we have on the parking lot a little bit, but we could bring any one of them back to the floor if it seemed that it were a particularly important issue to be addressing and we were the right folks to do it.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
In your work did you look at the laws of state laws and the commonality of how many categories are there that are uniformly specially protected in state law?

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
We have some state law information with respect to certain categories. I would tell you that the primary places where there is state law, and of course, state law is hard to get a handle on at any given time and it's all over the map with respect to some categories. But here are the ones where we find the most activity: Genetic information and special protection for the state level for the genetic information. Special protections at the state level with respect to HIV information, potentially other sexually transmitted disease information, special protections at the state level or a variety of different state laws ... with respect to the respected walls of adolescents and parents and consent to records.

There are also, of course, a lot of abuse reporting requirements that states have and abuse reporting categories differ. Child abuse is pretty uniform.

That's a very quick summary. One of the things we considered doing, but we don't have a lot of staff, is an actual, in the weeds look at state law with respect to one or another of these categories. We got, as part of our testimony, actually in the last hearing very good compendia about adolescents and parental consent.

Gayle Harrell – Florida – Former State Legislator
Leslie, I might suggest you contact the National Governor's Association. They have done quite a bit of coordination and research on this issue of where state laws are on a lot of this.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security

We have that done.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
We have all of that. The National Association of State Legislatures has it too. We've got all of that stuff. I've worked with ...

(Overlapping voices.)

Deven McGraw - Center for Democracy & Technology – Director
I think we need to start wrapping this up and talk about how we're going to plan to begin our discussion so that we can move to some public comment here.

Paul Egerman – eScription – CEO
I think that's right, Deven.

Deven McGraw - Center for Democracy & Technology – Director
Yes. We've got—

Paul Egerman – eScription – CEO
Back up. We're not quite ready for the public comments.

Deven McGraw - Center for Democracy & Technology – Director
I know. I didn't realize Altarum had done us the favor of advancing the slides because I was doing them for NCVHS.

John and Leslie, that was incredibly helpful and information that we will need to keep in mind as we think about how to take our set of recommendations on general consent into the sort of next step. How does that apply when you think about patient choice at a more granular level? So Paul and I started to sketch out some discussions, some questions for our discussion, which we had hoped to begin today, but which we will begin at the top of our call on Tuesday.

Gayle Harrell – Florida – Former State Legislator
Deven, I'd just like to make one comment. I want to really say thank you to NCVHS because of their framing things so well for us in that letter and also in categorizing things. To me the most basic thing they said was that the fundamental right of privacy should determine the architecture. I think that was critical to what I heard in this entire discussion and that that right should be used to determine the policy and that the policy should then determine the architecture.

Paul Egerman – eScription – CEO
Those are good comments, but Deven was on a roll trying to wrap up the meeting and unfortunately, we are on the clock. Deven, did you appreciate that comment?

Deven McGraw - Center for Democracy & Technology – Director
I think—

Paul Egerman – eScription – CEO
I certainly join you, Gayle, in thanking John and Leslie and NCVHS, because we want to work hand-in-glove with them and coordinate all of our work with theirs and vice- versa. There's no reason for two different groups to be doing the same thing. We have plenty on our plate and they've got plenty on their plate, so let's make sure we take advantage of what each other has done. We appreciate that.

I'm sorry. Go ahead, Deven.

Deven McGraw - Center for Democracy & Technology – Director
No. No. No. I can't say that I 100% understood Gayle's point, but we have plenty of time to bring it back up again on our next call.

Paul Egerman – eScription – CEO
Okay. So are you going to review these questions quickly, Deven?

Deven McGraw - Center for Democracy & Technology – Director
Yes, I can go right through them. So we sort of, again, consistent with first of all, thinking about the recommendations that we have already put on the table and gotten accepted from the Policy Committee, which is the full spectrum of fair information practices applies to the acquisition, use, disclosure and retention of all identifiable health information and similarly, the fundament principle that underlies patient choice that the foundation is a physician-patient relationship and the provider and the patient together making decisions about disclosure, how do you sort of take that to the next level and think about, number one, applying patient right to choose based on sensitive data categories in direct exchange, given that we had talked about choice in the context of the trigger factors being present. Now that we're talking more specifically about sensitive data do we want to think about this in terms of all models of exchange?

Number two, to what extent does current technology support the ability for EHR systems to segment data? This is a follow-on discussion of our consent technology hearing. To what extent does current technology support the ability of patients to control the flow of information per their preferences by data recipient, as well as by data category, what type of data? What can state HIOs do now based on technological capability? We can talk a little bit about a model that Maryland is using in order to give patients more choice. It's kind of a blend of provider exchange and health record bank/PHR model. What, if anything, should ONC be doing to provide incentives for these capabilities to be developed, if in fact, they are less mature than we would like?

With that in mind we will develop some slides, I think, if we can before Tuesday to try and flesh some of this out and guide the discussion a little bit, but again, our idea is to be building on what we have done in the past and taking this choice discussion to the next granular level.

Paul Egerman – eScription – CEO
Right. That was great, Deven. Just to clarify question number one, because I was talking to somebody about this last night. They said a patient's right to choose is sort of like a loaded set of words.

Deven McGraw - Center for Democracy & Technology – Director
Okay.

Paul Egerman – eScription – CEO
What we really mean by that, what we're talking about there is the consent of triggers. If you look at the presentation that we gave to the policy committee, on one slide we said no consent is required for directed exchange and then on another slide we said sensitive data is a trigger for consent, so people said which one is right. In other words, if it's sensitive data and it's directed exchange is there a consent involved. That's what question number one is. I want to be clear if that's what question number one is. The purpose of showing this to you in advance is hopefully to ask you to consider how you want to answer each of those questions and if people want to volunteer to send their thoughts by e-mail in advance of Tuesday's meeting that would be terrific.

Leslie Francis, Ph.D., J.D. – NCVHS – Co-Chair
I will send you thoughts by e-mail, because I'm probably not going to be available for that call.

Deven McGraw - Center for Democracy & Technology – Director
Okay. Great, Leslie.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I will not either. Any chance we could make it Monday?

Deven McGraw - Center for Democracy & Technology – Director
No.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Will you send out these slides so we'll have this list?

Deven McGraw - Center for Democracy & Technology – Director
You do. You have these slides. They were in the Judy Sparrow list. Anything that we would further develop for the meeting on Tuesday in response to e-ails that people send and some conversations that Paul and I and Joy could have in between now and Tuesday we would, of course, send to you before hand, assuming we can pull that off, but you've got these slides already.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Okay.

Paul Egerman – eScription – CEO
So it's been an excellent meeting. You can see by these questions we've got a really fascinating set of issues to resolve. We'll get to roll up our sleeves and do some interesting discussions.

Deven, do you think we're ready to open for public comment?

Deven McGraw - Center for Democracy & Technology – Director
I think we are, Paul. Thank you.

Judy Sparrow – Office of the National Coordinator – Executive Director
Okay. Good call. Operator, do you want to see if the public wants to make any comments on this, please?

Operator
You have a comment on the phone.

Judy Sparrow – Office of the National Coordinator – Executive Director
Great. Can that person please identify yourself?

Les Kepper
This is Les Kepper. I think this is one of the best discussion I've heard in over 40 years. I'm working at this and I'm very, very impressed with what you're doing. Keep it up.

Paul Egerman – eScription – CEO
That was one of the best public comments I've ever heard.

Deven McGraw - Center for Democracy & Technology – Director
It was.

Paul Egerman – eScription – CEO
I appreciate that, Les. Thank you very much. Actually, that's very kind of you. Lots of times we'll mainly hear criticism, so I really appreciate that.

Judy Sparrow – Office of the National Coordinator – Executive Director
Yes. Anybody else on the line from the public? Okay. Well, thank you, all, for a very nice call. Have a good weekend.

Paul Egerman – eScription – CEO
Yes. Good weekend to everybody.

Deven McGraw - Center for Democracy & Technology – Director
Have a good weekend, everybody.

Public Comment Received During the Meeting

1. HIO may not 'hold' any data. Most models only hold metadata.

2. If patient A tells the Dr. they do not want to participate in the data sharing, who informs an outside entity that the Dr. sends blood draws to for lab analysis to not share the data? The patient many times does not know who the other entity is to request to "opt-out".